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ABSTRACT

This manual is intended to provide the necessary information so that children and young people with disabilities can receive the money, health insurance, and other help to which they are entitled. Section 1 describes a model for assisting a family to identify their needs and goals and the types of benefits to which the child may be entitled. Section 2 describes Social Security benefits, assistance from the state of New Hampshire (such as Medicaid), and private health insurance. Section 3 includes information about programs for children and youth by age group, including programs for babies with disabilities, known as Family Centered Early Intervention; help for the student with a disability, including programs in the schools; and the process for transitioning out of school to the adult service system, including help with employment and residential services. Appendices include lists of the agencies which provide these benefits and programs, along with lists of agencies which can help the child and family understand and gain access to these benefits. (DB)

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BENEFITS PLANNING FOR CHILDREN AND YOUTH WITH DISABILITIES

by JoAnne M. Malloy

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2ND EDITION
1994

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by JoAnne M. Malloy

Funded and Published by

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BENEFITS FOR CHILDREN AND YOUTH

WITH DISABILITIES

AGE BIRTH TO 21

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- New Hampshire Bureau of Special Education
- New Hampshire Division of Vocational Rehabilitation
- New Hampshire Division of Human Services
- New Hampshire Division of Public Health
- The Social Security Administration

INTRODUCTION

This manual was written for young people with disabilities, their family members, and the professionals and friends who work with them. The manual has basic information about how to get the money, health insurance, and the other help for children and young people who experience disability from birth up to age 21.

All families and their children find it hard to pay for proper day care, training and health care. A child with a disability will have extra needs related to therapy, tutoring, medical care, education, training, and so on. It is hard to find one's way through the complex system of Social Security, public assistance, private insurance, and all the programs in the schools and the community.

This manual outlines, in basic terms, what is available to help children or youth with disabilities and their families. There are four major sections to this booklet:

SECTION 1: RESOURCE NEEDS AND PLANNING

SECTION 2: INDIVIDUAL BENEFITS
and HEALTH INSURANCE

SECTION 3: PROGRAMS AND SERVICES
PROVIDED BY AGE GROUP:
A. AGE BIRTH - 3
B. AGE 3-21 or GRADUATION
C. TO ADULTHOOD

APPENDIX

SECTION 1 describes a model for assisting a family to identify their needs and goals, and the types of benefits to which the child may be entitled. SECTION 2 describes Social Security benefits, assistance from the state of New Hampshire, including Medicaid, and private health insurance. SECTION 3 includes information about programs for children and youth by age group, including programs for babies with disabilities, known as Family Centered Early Intervention, help for the student with a disability, including programs in the schools; and the process for transitioning out of school, to the adult service system, including help with employment and residential services.

The appendix includes lists of the agencies which provide these benefits and programs, along with lists of agencies which can help the child and family understand and gain access to these benefits.

This manual does not describe every possible benefit a child or young person with a disability may be able to receive. Complex family situations (foster families, step families, etc.) may not be correctly described here. **IT IS IMPORTANT TO ASK FOR HELP FROM SOMEONE WHO KNOWS ABOUT ALL THESE PROGRAMS!** There is a Family Support Coordinator at every

regional Area Agency (listed in the Appendix). The coordinators have experience helping families understand the benefit system. Family Support staff can help families apply for benefits, understand their entitlements, and seek additional help when needed.

Each family's situation is different. If your experience is different than what is described in this manual, speak to someone who knows the rules well. A mistake with benefits planning now could be disastrous for the child and the family. If the family needs to develop a trust or will, speak to a lawyer. For advice about client rights, speak to a lawyer. Lists of Legal Assistance Offices, the Disability Rights Center, and other advocacy organizations are in the Appendix.

The manual describes the rules for many public resources. There is also a network of private resources available to families and young people. This manual does not take a philosophical position regarding what type of program is correct for each child or youth who experiences a disability. The intent of this manual is to provide information about where to get help. There are sections which include information about developing a program which centers around the needs and wants of the person with the disability. This manual attempts to include information about the person's options and to emphasize choice and individualization of services.

The information for this manual was taken from the Social Security procedure operation manuals, the New Hampshire Public and Medical Assistance manuals, state and federal rules for public education and vocational rehabilitation, and other public material. A great deal of information was taken from interviews with state agency staff and from the personal experiences of families and benefits planning staff. This manual is not an outline of official state or federal rules. Instead, it attempts to share information about how the system really works and how the child and family can be in control of what happens. It is important for the child and the family to have someone on their team who knows and understands the public and private system of resources.

JoAnne Malloy
March, 1994

I. RESOURCE PLANNING

WHAT IS RESOURCE PLANNING?

Children and young people with disabilities will often have needs related to health care, daily living, recreation, school and work which other children do not have. The child's family should identify and plan for those needs. Family support staff, attorneys, advocates and other professionals are available to help a family identify the child's goals and to plan for those costs.

This section offers a model for developing a list of needed resources. This model can be used as part of the Individual Family Service Plan, the transition planning process or the Individualized Service Plan process. Resource planning is an integral part of the service planning process.

The Family Support Coordinator at the NH Division of Mental Health and Developmental Services can also provide more information about long term care planning. An attorney knowledgeable about public assistance should be consulted for estate planning.

RESOURCE PLANNING MODEL

STEP #1: WHAT ARE THE FAMILY'S AND CHILD'S BASIC NEEDS?

Every family experiences times when basic needs such as money and health care are not being met. If a family is in such a situation, it is impossible to think about long range goals until those immediate needs are taken care of. This first set of questions deals with the basic needs for money and health insurance.

A. Does the child have health insurance?

B. Are the child's medical expenses greater than the family's ability to pay?

C. Does the child need therapeutic, educational or rehabilitation services not covered by health insurance?

*(If **yes to any of the above**, explore Medicaid, including Katie Beckett entrance criteria).*

TO DO:
- **Look at the possibility of qualifying for Medicaid**
- **If the family has health insurance, go over the insurance plan carefully**
- **Look at the possibility of getting help from Public Health**
- **Depending on the child's age, seek out help from a counselor, Family Support liaison, case manager, etc.**

D. Is the family's income around $1,800 per month or lower? Are there a lot of children in the family?
E. Is this a single-parent household? Is it a foster family? Or other type of family?
F. Does the family need more money?

TO DO:
- **Apply for Supplemental Security Income and Medicaid**

G. Is the "child" fourteen or fifteen years old?

TO DO:
- **Ask the school to begin transition planning with the youth. The school staff will help assess the family's needs.**

H. Does the child have a developmental disability?

TO DO:

•Contact the regional area agency to see if the child qualifies for services.

I. Does the child have a specific medical condition?

TO DO:

•Contact Public Health Bureau of Special Medical Services to see if the child qualifies for services.

J. Is the "child" a youth over 18, or about to turn 18?
K. Is the youth prepared to work or move out on his or her own?
L. Is the youth's situation putting financial pressures on the family?

TO DO:

•Apply for Medicaid for the youth (may qualify for Aid to the Permanently and Totally Disabled upon reaching age 18). Apply for SSI at same time. It is best to get onto these programs before going to work.
•Seek application with the NH Division of Vocational Rehabilitation.
•Seek application with the local Job Training Council program.

STEP 2. DEVELOP A STATEMENT ABOUT THE CHILD'S OR FAMILY'S VISION FOR THE CHILD THREE TO FIVE YEARS FROM NOW.

Once the pressure of meeting basic needs is reduced, a family or young person can begin to address longer term goals. This part of the process involves using both personal and program resources to obtain greater independence and security.

For example, the family of a two year old child with a developmental disability might develop a description of what they hope for the child at age five or six. The parents may see the child in first grade with other children, or see the child using a communicator, etc.

Another example may be of a youth who is fourteen. Does that student see him or herself working at a fast food place at age 17? Or in all regular classes? Or in all vocational education classes? What kind of diploma does the youth want to receive? What is the youth going to do after graduation?

This process is not appropriate for every child or youth. Obviously, the family of a child with a serious life-threatening disease is not going to want to engage in a visioning process. For those families, the goal-setting process must center around meeting child's medical needs as well as what the family and child needs on a daily basis to be comfortable and safe. **IF THE FAMILY'S AND CHILD'S BASIC NEEDS ARE NOT MET, THE VISIONING PROCESS IS INAPPROPRIATE.**

STEP 3. OUTLINING WHAT NEEDS TO HAPPEN TO GET TO THE GOAL:

How does a two year old infant's family work toward going into a regular first grade class by age six? Outline the steps without regard to "limitations," "disabling conditions," or any other roadblocks (analysis of limitations comes later). What would the process be for a child without a disability?

•Parcel the problem out into **manageable, short-term steps**

•Begin with the goal and **work backwards** (for the example, start at first grade and work back to the present).

•**Define this year's goals in very specific terms:** what is to be accomplished, how, who will do what and by what times? If there are more than three or four major goals to do right away, pick out the three most important and put the rest on the back burner.

For example, the two year old may need extra stimulation at home, which the parent wants to provide with support from an Occupational Therapist. The **outcome** is to bring the child's physical, cognitive and social development up to an appropriate level to enter pre-school next year (pre school being a necessary step toward first grade at age six). The **providers** will be the parents and occupational therapist. The **time frame** is when pre school for three year olds begins.

STEP 4. OUTLINE THE OBSTACLES

What stands between the child and this objective? Is it money? Availability of service? The rules do not allow it? With the example of the two year old, perhaps the Occupational Therapist has never worked with a parent in this type of situation. Perhaps the child has chronic medical problems which must be addressed. Perhaps the local day care centers are reluctant to accept the child, or they require "extra help" for the child. Perhaps the pre school is willing but lacks the knowledge to accept the child.

Each of the obstacles should be written out separately. Look at each and decide which ones are surmountable and which ones cannot be changed. The family can develop steps to address the surmountable obstacles. The family must modify goals to accommodate the obstacles which cannot be changed.

In the example, the two year old cannot change his or her chronic medical needs. The family decides to work around any lost time due to illness with a flexible therapy schedule. The family applies and qualifies for Family Centered Early Intervention. A case worker helps the family to develop a service plan, which includes applying for Medicaid. Once the family receives Medicaid, it will pay for the occupational therapy. The plan also includes transitioning into preschool for the next year.

RESOURCE PLAN

A. THE GOAL IS TO_____
(Express the goal as an outcome)

_____

_____by _____19____.

B. STEPS TO REACH THIS GOAL:

STEP 1_____

STEP 2_____

STEP 3_____

STEP 4_____

STEP 5_____ which has district offices throughout the state. Medicaid will provide the eligible child with an "insurance" card which is then presented to the doctor, hospital, pharmacist or other agency who gives the child care. Only

_____

_____

_____

D. THE TWO-THREE STEPS TO UNDERTAKE THIS YEAR:

Objective 1 _____
(express as an outcome if possible)
_____by_____19___

Provided by _____

Costs_____ Paid for by _____

TO DO:_____

_____.

Objective 2 _____
(express as an outcome if possible)
_____by_____19____

Provided by _____

Costs_____ Paid for by _____

TO DO:_____

_____.

Objective 3 _____
(express as an outcome if possible)
_____by_____19____

Provided by _____

Costs_____ Paid for by_____

TO DO:_____

_____.

Notes:

II. INDIVIDUAL BENEFITS AND HEALTH INSURANCE

SOCIAL SECURITY BENEFITS FACT SHEET

WHAT ARE SOCIAL SECURITY BENEFITS?

The federal government provides benefits to qualified workers who can no longer earn a living because of retirement or disability. Benefits can also go to the worker's dependents or surviving dependents if the worker has died. Minor children receive Social Security benefits as dependents of the retired, disabled or diseased worker. If the dependent child has a disability which occurred before age 22, that "child" can be an adult and still receive Social Security benefits.

WHAT DO SOCIAL SECURITY BENEFITS INCLUDE?

The beneficiary usually receives a monthly Social Security check. The dependents may also receive a Social Security check, up to a family maximum. The amount of the check depends on how much the beneficiary made as a wage earner. A dependent's benefit is tied to the wage earner's benefit. After two years, Medicare health insurance is usually provided to the wage earner and the dependents.

WHAT ARE THE BASIC BENEFIT RULES?

The rules for Social Security benefits differ depending on whether the wage earner is retired, disabled or deceased. A dependent unmarried child will receive the benefit as long as the parent receives benefits, until the child turns 18. An Adult Disabled Child collecting on a parent's benefit will continue to receive the benefit as long as that "child" remains disabled and unmarried. Medicare coverage is given to some groups of beneficiaries even after other benefits end. Social Security benefits are not optional so a person entitled to benefits usually must take those benefits.

WHAT HAPPENS IF THE CHILD RECEIVING SOCIAL SECURITY GOES TO WORK?

The Social Security benefit rules differ for people who work depending on the basis for the benefit. Retirees can work and make a certain amount of money per year without penalty. Disabled beneficiaries can work for 9 months before their benefit is evaluated. Dependent children and youth can work and make a certain amount of money per year without penalty. Disabled children over age 18 have their benefit evaluated on a monthly basis based on earnings.

HOW DOES A CHILD APPLY FOR SOCIAL SECURITY BENEFITS?

When a parent retires, becomes disabled or dies, that parent or survivor contacts the local Social Security office and provides information about the family. A child's benefit is tied to a parent's benefit. Any child or adult who experiences disability should be in contact with Social Security when that child's parent dies, retires or becomes unable to work because of long term disability. There is also a Social Security benefit for spouses of Social Security beneficiaries who stay home to take care of a disabled child, as long as the child is under age 16.

WHERE TO GET INFORMATION ON and HELP WITH SOCIAL SECURITY BENEFITS:

Call your local Social Security Administration office, the Family Support Coordinator in your region, your local Legal Assistance office, or the benefits specialist at the Institute on Disability. ***SEE THE LISTINGS IN THE APPENDIX***

SOCIAL SECURITY BENEFITS DEFINED

• **SOCIAL SECURITY BENEFITS** are for people who have worked and are now retired, disabled or for the surviving dependents of an eligible adult who has died. Social Security benefits are also paid to the spouses and children of the Social Security beneficiary. This means that the widow of a man who worked for many years and paid payroll taxes will get Social Security (she is "deemed" his dependent). This means that the minor or disabled child of a parent who retires and collects Social Security will get Social Security (the child is deemed dependent on the parent).

• **Social Security is NATIONAL RETIREMENT, DISABILITY AND SURVIVOR'S INSURANCE.** Almost every worker pays into the system through FICA payroll deductions, and the employer matches that contribution. Self-employed people pay 100% of the Social Security tax. Some state and federal employees have a different retirement system.

• **The amount a person collects in Social Security benefits relates to the amount that person paid into the system when they worked.** There is no "partial" or reduced benefit unless the person is also getting worker's compensation, took early retirees benefits, or is paying back an overpayment. The amount a child (natural, step-child, or illegitimate) receives can be up to 75% of the parent's benefit if the parent has died, up to 50% if the parent is getting retirement or disability. The child's benefit is "tied to" the parent's benefit. If the parent does not get a check, the child will not get a check, etc.

• **These benefits include a monthly check sent to the eligible person, and, when certain conditions are met, MEDICARE health insurance.** A person does not have to be low income to receive Social Security Benefits. People in all income brackets get Social Security benefits.

• **Social Security benefits are provided to "children" or young people** under three categories: *Child Dependent Benefits, Disabled Child Benefits, and Social Security Disability.* The first two categories are for children of a parent who receives Social Security benefits. The last program is for young people who have worked enough to get their own Social Security, but are not able to work at a substantial level.

HOW TO RECEIVE SOCIAL SECURITY BENEFITS:

Each applicant must go to the local Social Security Administration (SSA) office to apply for benefits or call to apply over the phone. The eligibility rules to qualify for benefits for children under the three categories are:

1. ELIGIBILITY FOR CHILDREN'S BENEFITS:

• The child is under 18 years old (under 19 if a full time student in secondary school).
• The child's parent receives Social Security Disability, Retiree benefits or the parent has died.
• The parent must have worked, paid Social Security taxes, and be "insured".

2. ELIGIBILITY BENEFITS FOR ADULTS DISABLED SINCE CHILDHOOD:

• The applicant must have a disability which started before age 22, and the applicant is now at least 18 years old.

• The applicant's parent collects Social Security benefits, or has died. The applicant's parent is eligible for Social Security benefits.

• The applicant has a disability which prevents that person from working at any great level (called the "SGA" or Substantial Gainful Activity level).

3. ELIGIBILITY FOR SOCIAL SECURITY DISABILITY BENEFITS:

• The applicant has worked and paid FICA taxes to the federal government for enough calendar "quarters" (a quarter is three months). Some youth who have worked may qualify under these rules.

•The applicant must have a disability which limits that person's ability to work and earn a living. A doctor must supply a written assessment of disability. The Social Security Administration uses that information to evaluate the person's eligibility.

HOW SOCIAL SECURITY DECIDES IF A CHILD IS DISABLED:

The Social Security Administration will usually not need disability information about any child under age 18 (that child is a dependent and so disability status is not a factor for the child's eligibility). For "Adult Disabled Child" benefits, however, the Social Security Administration will need proof that the "child" has a disability.

The Social Security Administration first verifies that the child is not working and earning high wages (earnings consistently over $500 per month). If the child cannot work, then Social Security will contact the child's doctor and will also seek hospital records, reports from therapists and teachers, etc. They will also ask the parent about the child's daily functioning. The Social Security Administration then sends this information to the disability examiners and doctor at the Division of Vocational Rehabilitation. The child's diagnosis is then compared to a List of Impairments. The examiner tries to decide if the child's condition interferes with everyday life. They look at whether the child can complete tasks as do other children that age. If the child's disability is on the List of Impairments, or if the child's abilities are limited compared to other children, *and* if the disability will last at least a year, if not for the child's lifetime, then the child qualifies as disabled.

USING SOCIAL SECURITY BENEFITS:

Social Security benefits are insurance entitlements designed to make up for lost income because the person cannot work. A qualified child cannot technically turn down Social Security Benefits to which he or she is entitled. A child's Social Security check should be used to meet the child's current and future needs. It might be wise for a child receiving Social Security to save the money for costs which may come up later, such as training, college or housing costs.

Sometimes a parent must stay home (and cannot work) to take care of a child with a disability. The spouse who stays home to care for the child of a Social Security Beneficiary may receive a benefit which" helps the family make up for income lost because one parent must stay home to care for a child with a disability.

HOW MEDICARE WORKS:

Medicare health insurance goes along with Social Security benefits when a beneficiary turns 65 years old or after two years of receiving a disability benefit. Upon qualification for Medicare, the beneficiary will be sent a red, white and blue Medicare card. The doctor, pharmacist or clinic where that person receives services or goods must agree to bill Medicare. Not every doctor or provider will agree to honor the card.

Medicare covers 100% of some costs including major hospitalization after a deductible is met. Hospitalization coverage through Medicare is called "Part A", and is free to the beneficiary. Outpatient coverage has a monthly premium (called "Part B"). In 1994, the premium is $41.10 per month. This optional coverage includes therapies, outpatient visits, etc. There are caps and limits on services and equipment, and, in some instances, Medicare will not pay the whole bill. There is a Medicare booklet available at the local Social Security office which covers specifics about the Medicare program.

WHEN SOCIAL SECURITY BENEFITS END:

• For a child beneficiary, benefits will end when that child's parent benefit ends or when the child turns 18 (19 if the child is a full time student in secondary school, whichever comes first).

• For the Adult Disabled Child beneficiary, benefits end when the parent's eligibility ends, or when that "child' works or Social Security believes the child can work at a Substantial level (earnings of over $500 per month). The same is true for a Social Security Disability beneficiary. Social Security benefits continue for at least a year, and sometimes longer, when a beneficiary first goes to work. Benefits end at any time if the "child" medically recovers.

• Children's benefits, including Disabled Adult Child benefits will end when that child marries.

SOCIAL SECURITY BENEFITS FOR CHILDREN and YOUTH WHO WORK:

• Dependent Child beneficiaries and Adult Disabled Child beneficiaries receive benefits because they are deemed dependent on a parent who receives Social Security benefits. **If the parent works and loses benefits, the child will also lose benefits.**

EXAMPLE:

Alice W. receives a monthly Social Security check of $325. Alice is 15 and her father receives Social Security Retiree's benefits. Alice's dad works part time. Alice and her dad will receive only part of their twelve month SSA benefit because Alice's dad earns more than the allowable annual exempt amount. A related problem is that during those months they do not get a Social Security check, Alice and her dad have to pay for their Medicare Part B premium, which is deducted from the Social Security checks when they receive checks.

• A child of a parent who died is entitled to Social Security benefits until that child turns 18.

• An adult who receives Social Security benefits as an Adult Disabled Child Beneficiary is subject to the Social Security Disability rules about adults who work:

- Social Security benefits will continue for the first year the person works, no matter how much the person earns.

- After the first year of work, benefits will end for any disabled beneficiary who earns over $500 per month.

- The value of goods and services the person needs in order to work can be deducted from counted wages. Vocational services, equipment, training, etc., are all deductible. These deductions are called Subsidies and Impairment Related Work Expenses. Any beneficiary who works must tell the Social Security worker about any expenses that person has or help that person receives to work. Social Security needs to know if the person is getting help on the job, help from school teachers, or any other kind of help related to working.

• It is wise for families and young people to try to **put some Social Security income into savings.** It is easier for a child or young person to save while still at home.

• A person can save or set aside Social Security benefits for a work goal by writing a Plan to Achieve Self Support. *(See: PASS in Supplemental Security Income Section)*

For more information on work, see Benefits Planning Guide for Adults, available at the NH Developmental Disabilities Council.

IF A BENEFICIARY DISAGREES WITH A SOCIAL SECURITY DECISION:

• **APPEAL, APPEAL, APPEAL!** The disability examiners make judgements based on reports about people they never see. There is evidence to suggest that if a person appeals the decision will be overturned.

• There are four levels in the appeals process:

1. Reconsideration: The application is reevaluated by a different disability examiner.
2. Administrative Law Judges (ALJ): At this hearing, lawyers, parents, vocational experts, etc., and may look at new evidence. The applicant may also appear in person and state his or her case.
3. Appeals Council: will look at the ALJ hearing and may or may not request new evidence
4. US District Court: Some cases are brought to the US courts. These are usually cases involving how SSA determines disability brought by people who were turned down for benefits.

• **Sometimes Social Security beneficiaries are overpaid** - The Social Security Administration continues to send checks to them even after they are no longer eligible for benefits. Later, the beneficiaries must pay money back to the Social Security Administration. If the person genuinely cannot pay back the money owed, or that person needs to arrange a payment plan, contact the local Social Security office and ask for a "Waiver from Overpayment" form or ask to make a repayment agreement. To qualify for a waiver, the person must show that he or she was not at fault for the overpayment and that he or she cannot afford payment back to Social Security.

HELPFUL HINTS

• ***Get help from a family support staff member, lawyer, case manager or other advocate.*** *The language and rules of the Social Security Administration programs are complex, unfamiliar and can be difficult to understand. Ask the Social Security staff if you do not understand something.*

• ***Save every letter from Social Security.*** *Create a file and keep every letter. Some people don't want to read the letters, but they contain excellent information about beneficiary rights, appeals procedures, time frames, and decisions about the benefit.*

• *Establish a* ***good relationship with Social Security.*** *Professional staff should accompany applicant and beneficiaries to meetings with the Social Security Benefit Technician. Local service providers should make a point of getting to know local* Social security staff. Good communication helps to eliminate misunderstandings regarding beneficiaries and programs.

• ***Report any changes immediately,*** especially changes in income, to the Social Security Administration. This will avoid large overpayment situations.

SOURCES:

U.S. Department of Health and Human Services, Social Security Administration, Procedures Operations Manual, 1973-1992.

U. S. Department of Health and Human Services, Social Security Administration, Office of Programs, Office of Disability, Red Book on Work Incentives, June 1991, SSA Pub. No. 64-030, ICN 436900.

SUPPLEMENTAL SECURITY INCOME (SSI) FACT SHEET

WHAT IS SUPPLEMENTAL SECURITY INCOME?

Supplemental Security Income (SSI) is a federal benefit program for low income children, low income adults with disabilities, and low income elderly people, given out through the Social Security Administration (SSA). The Social Security Administration defines child as a person, age birth to 18 who is low income and experiences a disability which severely limits that child's functional ability relative to other children the same age. Part of the parents' monthly income and assets are counted when a child receives SSI. When a person turns 18 years old, parental income and parental resources are no longer counted.

WHAT DO SSI BENEFITS INCLUDE?

Each child who receives SSI may receive a monthly check, up to a maximum of $446 in 1994. This maximum amount usually goes up every January (called the Cost of Living increase). The amount of the SSI check depends on the family's income, and will change if the family's income changes. There is a special SSI program for people who work called the 1619 Work Incentives. This program allows a person's name to stay on the SSI rolls even after that person is earning too much to get an SSI check, up to maximum wages of $23, 924 per year (1994 NH figure).

HOW DOES A CHILD QUALIFY FOR SSI?

The Social Security Administration first establishes that the child's income and resources are below the SSI standards. If the child qualifies based on income, the Social Security Administration requires documentation of the child's disability. The rules require that a child have a medical condition which is verified by a doctor, and which limits the child's functional abilities.

TO FIND OUT MORE ABOUT SSI:

The child, parent or advocate should call the local Social Security Administration office for more information and to apply for SSI. The local Family Support Coordinator, the Family Support Coordinator at the NH Division of Mental Health and Developmental Services, an area agency or mental health center case manager, Legal Assistance, or the benefits specialist at the Institute on Disability can also help with information or filling out the required application.

(See listings in the Appendix)

Supplemental Security Income

SSI BENEFITS DEFINED:

Supplemental Security Income (SSI) is a federal program to provide cash assistance to children and adults with disabilities who are low income. The qualified SSI recipient will get a monthly check. An income formula determines the amount of the SSI check. **The amount of a child's SSI check depends on the amount of the child's income and resources, which includes some of the parents' income and resources. The amount of the check will vary as income varies.** The highest possible SSI check is $446 per month (1994).

A child eligible for SSI will begin to receive one check per month, based on what Social Security estimates that child's income will be for that month. The first month's check might be smaller because it is for only part of a month. The amount due to the child is adjusted every three months. If the child's and parent's income remains steady, the amount of the SSI check will not change. If income goes up, the SSI check amount will go down, and visa versa.

HOW A CHILD QUALIFIES FOR SSI:

SSI HAS *TWO MAJOR ELIGIBILITY REQUIREMENTS:* (1) INCOME, and (2) DISABILITY

For a child under 18 years old:

- The child must prove disability according to the Social Security rules

- The child's income, plus part of the parent's income are counted according to a formula and must come in under income guidelines

- The family's assets must also be under the guidelines.

INCOME REQUIREMENTS:

To figure SSI income eligibility for children under age 18, the SSI formula counts part of the parent's income and resources. This amount is added to the child's income and resources. This is what Social Security calls *"deeming"* some income from parent to child.

For people age 18 or older, parental income is not included as part of the applicant's income. An applicant who lives with parents or in a situation where someone else pays all the expenses will receive an SSI check based on two-thirds of the $446 SSI maximum. This is because the applicant in receiving "in-kind support and maintenance" from the family.

The Social Security Administration (SSA) counts some of the parents' assets as available to the child under 18. An asset is cash or anything which is easily converted to cash including all bank accounts, stocks, bonds, trust income, insurance policies, second cars, etc. The first $2,000 in a one parent household and $3,000 of assets in a two parent household are not counted. Above these amounts,

the parent's assets are deemed available to the child. The child must have under $2,000 in assets in order to get SSI. Items which are not assets are burial plots, the primary home for the family, one car valued up to $4,500, and trusts which are set up to be unavailable to the person who is applying for SSI.

SSI MONTHLY INCOME LIMITS FOR CHILDREN:

For example, in 1992: If the parents work, and that is the household's only income, then the child may qualify for SSI if the income limits* are under:

Number of other children with no disabilities in the household	One parent Household	Two parent Household
0	$1,443	$1,889
1	$1,666	$2,112
2	$1,889	$2,335
3	$2,112	$2,558

** Note: These income limits will change periodically.*

The SSI program does not count as income financial assistance from Aid to Families with Dependent Children (AFDC), expenses for a Plan to Achieve Self Support (PASS), other state and local aid, etc.

How people 18 and older qualify for SSI:

The Social Security Administration considers anyone over age 18 to be an adult. The parent's income is no longer deemed to the youth. The applicant's income and resources alone are counted for eligibility for adults.

- The person must prove disability according to the Social Security guidelines.

- The person's income and assets must fall under the SSI guidelines.
  - The most an adult or child can get in an SSI check each month is $446.
  - The most an adult can have in assets is $2,000.

- If the person lives in a home where someone else pays the mortgage or rent, and other household expenses, the amount of the person's SSI check will be two-thirds of the maximum.

FOR STUDENTS TRANSITIONING TO ADULT LIFE

A young person with a disability who turns 18 may be eligible for SSI because parental income is no longer counted. When a child is under 18, some of the parent's income is countable. Any young person with a disability should go to the Social Security office when that person turns 18 to apply for SSI.

DISABILITY REQUIREMENTS:

The first step for SSI eligibility is a quick check of the parent's and child's income. If the child's and parent's income is far above the income levels, the process stops there. If the child is working and making more than $500 per month, the application is denied. If it seems the child may meet the income guidelines, then the medical information and detailed income information is gathered.

The **Disability Determination Service (DDS)** is a branch of Vocational Rehabilitation which processes all SSA disability applications. The DDS receives the medical documents and compares the person's diagnosis against the List of Impairments. The child is approved for disability status if the child's documents show an impairment on the list. If the diagnosis is not consistent with the listing, The Social Security Administration must decide if the child's disability is consistent with the SSA definition of disability.

THE ZEBLY LAWSUIT

Until two years ago, Social Security used only a medical severity test to evaluate a child's eligibility for SSI. *This test, by itself, was proven inappropriate to evaluate children. and was the basis of a lawsuit,* Sullivan vs. Zebly. *The lawsuit decision stated that it was unfair to judge children against this standard. The Social Security Administration lost that lawsuit and now defines disability for children to mean that the child has a disability of "comparable severity to an adult with a disability", which includes an evaluation of the child's functioning, in addition to the medical criteria.. For the child, the disability must severely limit the child's ability to function relative to other children the same age. There is a List of Impairments for children, along with certain developmental milestones which a child should meet. This list becomes a major way for the disability examiners to decide whether or not a child qualifies as disabled. It makes sense to appeal the decision if the application is denied on medical reasons. Approximately half of the denials are overturned upon appeal, especially if the appeal goes to the Administrative Law Judge level.*

HOW TO APPLY FOR SSI

The family can apply for SSI by going to their local Social Security office. A Social Security Representative can go to the family's home if necessary. The Social Security benefits technician will ask for basic information about the child including proof of birthdate, citizenship, social security number, etc. The parents will need to show identification, marriage certificate, etc. Applicants also need to show income verification from all family members who work, bank accounts, real estate information (other than primary home), other resources and car registration. The Social Security representative will also ask for names and addresses of all medical providers.

The parent's report about how the child functions at home is *very important* information for the reviewers. Social Security will also gather information from doctors, teachers, therapists and any other professionals who can paint a complete picture of the child's condition. The parents should also supply copies of the child's medical records, as this can help to speed up the decision-making process.

Once the written information is submitted to the Social Security Administration, the disability information is sent to disability examiners. The disability determination process should take two to four months, but there is no legally required time frame for a decision. If an applicant has not heard from SSI within three months, it wise to call the local Social Security Administration office to find out the status of the application. The child's first SSI check may be retroactive to the date the child applied.

HOW SSI BENEFITS CAN BE USED:

• **The SSI check for a child is for the benefit of that child.** Most families who receive SSI need that money. The parent is usually the child's **"representative payee."** This means that the parent may need to show evidence that the child's SSI check is being used for the child's benefit. The representative payee is responsible for reporting income which the child or family receives.

SSI BENEFITS CAN END WHEN:

• A child or youth is **no longer considered disabled**, or,

• The child's or youth's **income or resources exceed the limits**

• **The child receives other benefits** which add up to more than the SSI limit, such as Social Security Disability Insurance, Veteran's benefits, Workers Compensation, unemployment, child support or any other type of unearned income. State or local welfare payments, medicaid, food stamps, etc., do not effect SSI payments.

WHEN A CHILD OR YOUNG PERSON ON SSI WORKS:

Part of the reason a child or young person can get SSI is because that person is not capable of working at earnings of over $500 per month. Once a person is on SSI that rule is no longer important. The SSI program rules are designed to make it financially easy to go to work:

• If a child on SSI goes to work, that child's SSI check will be cut back according to a formula. For the person who works, **the SSI check is cut by less than 50 cents for every dollar the child earns.**

• Children and adults on SSI will stay on the SSI rolls until their income from work are over the state threshold (in 1994, income of $23, 924 per year). This may mean that even if the individual's income from work is too high to get an SSI check, that person's name will remain on the rolls. If that person's income drops, that person will not have to reapply in order to resume SSI benefits.

• In addition, **children (including youth up to age 22 who regularly attending high school) can earn up to $1,600 per year (no more than $400 in a month) without any reduction in their SSI check.**

• **Any disability-related expenses an SSI recipient needs to pay for in order to work are deductible from counted earned income.** These expenses, called **Impairment Related Work Expenses (IRWES)** are then subtracted from earned income and may mean a higher SSI check.

• The SSI program also allows recipients to write a **Plan to Achieve Self Support (PASS)** and set aside income for a work goal. *(See Section on PASS)*

THE DRAWBACKS OF THE SSI PROGRAM:

• The amount of the SSI check changes as the individual's income changes. For example, a check for March is actually based on January's income, and is often based on estimates. As a result, people on SSI are often getting **over- and under payments from SSI.** A person who works may get too much SSI for a few months, and be overpaid. If that person's income drops back down, the amount of that person's SSI check may not increase for a few months.

• To stay on SSI, **assets must remain below asset limits**. This discourages saving. The exception is when a person has asked for a waiver of asset limits because of a Plan to Achieve Self Support.

SPECIAL NOTE: SSI BACK PAYMENTS TO CHILDREN WHO APPLIED FOR SSI IN THE 1980's AND WERE TURNED DOWN:

The Social Security Administration revised its SSI rules for children as a result of the Zebly lawsuit challenging the way Social Security evaluated child disability. The Social Security Administration must now try to locate any person who applied for and was denied SSI as a child based on medical reasons, between 1/1/80 and 2/11/91. Even if the applicant is now an adult,

Social Security must reopen the case and re-evaluate that person's eligibility for that period. ***IF A CHILD APPLIED FOR AND WAS DENIED SSI BETWEEN 1/1/80 and 2/11/91 BASED ON DISABILITY, THAT CHILD SHOULD CONTACT THE LOCAL SOCIAL SECURITY OFFICE AND HAVE THE CASE REOPENED AS PART OF "THE ZEBLY DECISION."*** *To find out more about the Zebly decision call the local Social Security office. A special office has been set up to answer questions and help people reopen their SSI cases, through the Mental Health Law Project at 1-800-523-0000. Children and adults have received retroactive SSI payments as a result of the Zebly decision. Sometimes this has meant a large retroactive payment to the individual. In some cases, the family has sought help to develop a financial plan or trust for the child because the large retroactive payment has jeopardized other benefits such as Medicaid. See the Advocate section in the Appendix for resources regarding trusts or lump sum planning.*

FOR HELP WITH A SSI APPLICATION:

The Social Security staff will help applicants fill out the SSI application. Help with applications is also available from area agency Family Support Coordinators, community mental health center staff, the NH Division of Developmental Services Family Support staff, or JoAnne Malloy at the Institute on Disability (603) 228-2084. A list of advocates is in the Appendix.

FINAL NOTES:

• **Save all letters from SSI.** The letters and notices from SSI have valuable information about the individual's rights, time frames for appeals, or why a benefit amount may have changed or stopped.

• **Appeal, appeal, appeal!** It is worthwhile to appeal any denial for SSI benefits with which you do not agree.

• **Expect over - and underpayments when the individual's income changes.** *See Social Security Section regarding waivers from overpayments.*

• **Report all changes in income immediately to the Social Security Administration.** The sooner the person reports a change in income, the sooner the SSI check can be adjusted and avoid high over - or under payments. Most changes can be reported to SSA by phone at 1-800-772-1213.

PLANS TO ACHIEVE SELF SUPPORT (PASS)

People who are on SSI are low income. The U.S. Congress realized that people on SSI may have a difficult time getting a good job and getting off SSI. The PASS program gives the SSI recipient one way of purchasing services, training or education, equipment, support, or whatever that individual

needs to help the person get a good job. The PASS is available to anyone who receives or could receive SSI, including youth under age 18 who are old enough to work.

The Plan is a contract between Social Security and the SSI recipient. There is no form to fill out but a recommended format is at the end of this section. Through the PASS, the SSI recipient proposes to spend or "set aside" a certain amount of money per month. The money set aside is non-SSI money such as Social Security benefits, wages, Veteran's check, etc. The Social Security Administration determines that person's SSI check amount based on disregarding the PASS set aside dollars. As a result, the person can purchase a service, equipment, etc., without suffering financially.

THE RULES FOR A PASS:

• The individual must be **getting SSI or capable of getting SSI** as a result of writing the plan. For example, a person who gets $550 per month in Social Security benefits is over income for SSI. If that person proposes a PASS with $400 per month in expenses, there is only $150 per month in Social Security benefits ($550 minus $400). Social Security of $150 per month is low enough to get SSI.

• The plan must be in writing, and it *must include:*

- -An occupational (job) goal
- -The month and year the goal is to be reached
- -The individual's name, address, date of birth, Social Security number
- -A budget of monthly expenses and income
- -How the money is to be spend or set aside
- -How the plan will help the individual get to a job goal
- -How the money will be tracked
- -Timeframes for the PASS
- -It must be signed by the applicant or guardian

• Children and adults on SSI can write PASS plans, as long as it relates to an occupational objective.

• **A PASS can be for up to 18 months**, with another extension for up to 18 more months. A PASS written for education or training can last an additional 12 months.

• The SSI recipient can have only **one PASS per job goal.** If an individual changes job goals, that person may write another PASS.

• **The Social Security Administration can waive the asset limit** for individuals with a PASS, allowing them to save more than $2,000 in their bank accounts.

THE PASS IS INTENDED TO HELP PAY FOR SOMETHING THAT WILL HELP THE PERSON TO REACH A JOB GOAL. IF THE EXPENSES ARE NOT RELATED TO GETTING TO SOME FUTURE JOB, THEN IT IS NOT A PASS-ELIGIBLE EXPENSE.

EXAMPLE OF A PASS:

Martin R. is 17 and a junior in high school. Martin attends mostly regular classes, but he is not doing well academically and he would prefer vocational training. The school has agreed to send Martin to a few vocational classes for next year. Martin has a Vocational Rehabilitation counselor, and has received an application for the technical college where he would like to take a one year building trades course. The DVR counselor will help Martin with the application for school as well as a PELL grant, but Martin will still need to spend about $180 per month for transportation, books and other fees. Martin's parents are not poor, but they are not rich either. Martin can stay in high school until he turns 21 years old, but he wants to move on like everyone else (staying in school means he will receive free educational services from the school for two more years). Martin receives $230 per month in Social Security because his mother died three years ago. Martin also gets $74 per month in SSI (some of his father's income lowers Martin's maximum SSI). Martin could spend $180 of his $230 SSA check on school at the tech by writing the PASS, and his SSI check will increase by about $150 per month. making up most of the difference.

HOW THE PASS IS APPROVED:

The individual's representative at the local Social Security office receives and decides on the PASS. That person will determine if all the needed information is included. They will decide if the plan looks reasonable and whether or not the plan shows that the person can reach the goal. The SSA representative must tell the individual what is wrong with the plan and how to make it better if the PASS is denied. It should take no longer than 6-7 weeks to get word on the PASS, although there is no legal time limit.

HOW THE PASS WORKS:

The individual will see an increase in the SSI check beginning with the month the PASS is approved. This is because SSI is not counting those PASS monies when figuring the SSI check amount. The individual must begin to spend or set aside the amount specified in the plan. It is easiest to use a checking account to show the correct amount has been spent. The SSI check amount will vary during the PASS according to income changes as for any SSI recipient. Changes to the PASS are made by written request to the Social Security Administration representative.

The SSI recipient **controls how the PASS monies are spent.** This allows the person with the disability to control when, where and how the money is spent.

WHAT THE PASS FUNDS CAN PAY FOR:

If the person can successfully make the case that the PASS expense will lead to greater employability, then it meets the requirements for the PASS. People have PASSes to pay for:

• monthly medical costs

• equipment and supplies needed for work
• tuition • books
• job coaches • on the job training •tutors
• transportation
• payments on small business loans or school loans
• expenses to start up business
• self-employment expenses, etc.

A PASS may be for any item, service or support which will help the individual to *become more employable.*

A QUICK TEST FOR PASS ELIGIBILITY:

• Do you get Social Security, or some other unearned income? *and/or*
• Do you now have partial or no SSI? *and/or*
• If you paid for the expenses you need to get to your goal, would you then be able to get SSI?

If **yes,** go on:
• Do you have a defined work goal with expenses in mind?

If your answer to the last question is **"yes"**, you may be able to use a PASS to get some of the money you need for these expenses.

LIMITATIONS OF THE PASS:

• The PASS is designed to help the person get off SSI, or to help the person to be less reliant on SSI. PASSes are not appropriate for expenses the person will always have.

• **If a person already gets the SSI maximum, they will not get more by writing A PASS.** For example, an individual who gets the maximum $446 per month in SSI, and who has no other income should *not* write a PASS. A PASS allows the individual to exclude income other than SSI, such as Social Security, wages, etc.

• **During the PASS the individual must track how the money is spent.** If the person cannot show how the money was spent, the PASS will end and the person could be required to pay back any increased SSI payment they had already received.

PASS WORKSHEET

Name:_____
SS#:_____

Address:_____

Date of Birth:_____

Summarize your current situation: Include disability, work and education history, living situation, benefits, goals, agencies working with you, etc.:

1. Occupational Objective:_____

2. Month/year you expect to reach the objective:_____

3. Planned expenditures for achieving this objective (use another sheet, if needed):

Item	# of Months	Connection to Objective	Cost per month	Total

4. What money and property do you have now or own that will be used toward this objective (Identify items and their value, provide account numbers where applicable, SSDI, savings bonds, etc.)

5. What income and property do you expect to receive that will be used to achieve the objective (identify amounts and sources such as wages, grants, loans, etc.)?

6. Are you working or saving toward the goal now? How? When did this activity start? How will you provide an accounting for these funds?

Your Signature/Date _____

Signature and telephone of person who helped with this plan:

_____

For details about the PASS, see SSA PASS Circular

Sources:

U. S. Department of Health and Human Services, Social Security Administration, Procedures Operations Manual, SSA.

Social Security Administration, "Red Book on Work Incentives," June, 1991. SSA Pub. No. 64-030, ICN 436900.

Mental Health Law Project, "The Advocate's Guide to SSI for Children," Julie Clark, Joseph Manes, 1992, Washington, DC.

Benefit Planning Guide for People with Disabilities in NH, JoAnne Malloy, 1994 Edition, Concord, NH.

MEDICAID AND STATE AID FACT SHEET

WHAT IS MEDICAID?

Medicaid is a federal program to provide health and long term care services to poor people in certain categories. New Hampshire operates Medicaid through the Division of Human Services which has district offices throughout the state. Medicaid will provide the eligible child with an "insurance" card which is then presented to the doctor, hospital, pharmacist or other agency who gives the child care. Only certain services are covered, and only providers who participate in the Medicaid program will be reimbursed.

WHAT DOES MEDICAID COVER?

Medicaid is more than the conventional health insurance program and covers a variety of services and equipment depending on the child's situation. For any child up to age 21, Medicaid covers comprehensive regular medical and developmental evaluations, routine medical care, hospitalization services, dental services, etc. For children who have an identified special need, Medicaid may be able to pay for therapies, early intervention services, equipment and supplies, special services provided in and by the school, psychological or psychiatric services etc.

HOW DOES A CHILD QUALIFY FOR MEDICAID?

Medicaid categories for children end at age 18, except for the CHAP services. There are several different ways children may qualify for Medicaid. Children in homes where there is a "problem," (poverty, abuse, etc.) may qualify for Medicaid. Children born after September 30, 1983, may qualify for Medicaid based solely on the family's income. Older children must meet a either a deprivation or disability and income criteria to qualify for assistance. Only one category, the Home Care for Children with Severe Disabilities (HC-CSD), known as the Katie Beckett program, does not require the family to be low income (the child must have income below certain limits). For children born before October 1, 1983, the family's resources (assets) are also counted and must be under state limits.

FOR MORE INFORMATION ABOUT MEDICAID:

To apply for Medicaid, the parent must go to the local district office of the NH Division of Health and Human Services (listed in the Appendix). The Family Support staff, the Statewide Family Support Coordinator, Legal Assistance, the benefits specialist at the Institute on Disability, the area agency or mental health center case managers may also provide help and information regarding Medicaid.

MEDICAID DEFINED:

The federal government passed laws and rules requiring health assistance for poor people and people with special needs in every state. Each state runs a version of this program. This program is called **Medicaid.** New Hampshire provides Medicaid through a state agency called the New Hampshire Division of Human Services (DHS). There are 13 DHS District Offices in New Hampshire.

The Medicaid program is very complicated. It is more than just a health insurance program. The Medicaid rules allow for states to set up the program to meet the needs of people in that state. In New Hampshire, Medicaid pays for more than just doctors visits or other medical services. It can also pay for early childhood rehabilitation services, equipment for a child with a disability, home health services, dental care, therapy, etc.

This manual provides general information about some of the ways children and young people with disabilities may be able to receive Medicaid. The information here describes eligibility for six basic groups: **1) Medicaid and financial help for children in the lowest income families, 2) Medicaid for children in certain age groups in low income families, 3) Medicaid for children with disabilities, 4) Medicaid for children with severe disabilities regardless of parent's income, 5) Medicaid for Adults (people age 18 or over), and, 6) Special Groups.**

There are many different ways for children to qualify for Medicaid, including in families where the parents cannot work, broken families, children with severe disabilities, and in families where the children require skilled level care. This section outlines how children may qualify for Medicaid, and some ideas how Medicaid can help the family and child.

THE WAYS A CHILD CAN QUALIFY FOR MEDICAID:

A. Medicaid and Financial Help for Children in Low Income Families (AFDC)

To be eligible for this category, there must be:

• There must be at least one child in the household who is under 18 years old, or under age 19 and a full time student who is still in high school

• The family's income must fall under certain **income levels.** The level depends on the number of dependents in the home

• There is **no disability requirement**. but there must be **a reason why the child(ren) are deprived of support and care.** Usually, this means that it is a single-parent household where there has been a death, a divorce or legal separation. If it is a two parent household, one or both parents must be receiving SSI, or one or both parents is "incapacitated" (unable to function as a parent or to work), or the primary wage earner in the home is working less than 100 hours per month.

• and, the family's resources (cash or items easily converted to cash) are below $1,000 to get cash assistance. For Medicaid only, the family's resources must be under $2,500 for a group of one, $4,000 for a group of two, and $100 for each additional person.

In this category of assistance, the family's income is assessed after some deductions are taken. The family's total income is run through a complicated formula, and then compared to an income standard which depends on the size of the family, the ages of the children, and the parent's situation (for example, one parent may be disabled, or the family may receive child support, etc.). If a family is low income, and meets the "deprivation requirement" as stated above, the family may qualify for financial and medical assistance. With somewhat higher income, the family members may qualify for medicaid only (see some of the following medicaid categories). The income limits change at least once per year, so check with the local district Human Services office to find out about current income limits.

The amount of money a family gets depends on that family's income and the number of dependents in that home.

The family that qualifies for AFDC will also qualify for food stamps. The family needs to apply for food stamps and can do so at the same Division of Human Services office.

If a family's income is too high for AFDC cash assistance, but they meet all the other AFDC requirements, they may qualify for **Medicaid In and Out** (see below).

B. Medicaid only for children in low income households

Sometimes the family's income is too high to receive financial help or the family does not meet the "deprivation requirement" described above. There are higher income limits which may allow the family to receive **Medicaid only for the child(ren).** Medicaid is available under the following:

- Poverty Level Children - The child was born after 9/30/83.
- Children's Medical Assistance (CH) - For children who do not meet the income criteria but have medical bills in excess of the family's ability to pay.
- Medicaid for Children with Severe Disabilities - The child is under age 18 and has a disability.

To qualify for one of these programs the child must:

- Be under the ages as specified in each category above

- **The child(ren) does not have to be disabled except in the Children with Severe Disabilities category.**

- **The family does not have to meet a "deprivation" requirement** (such as divorce, single parent, disabled parent, etc.)

• The child must be under certain income limits, determined by the child's income, the child's parents' income, the child's age and the number of people in the household.

If the child lives with his or her parents, some of the parent's income is considered available to the child according to a formula. The resulting household's net income must be under certain income limits.

If the child does not live with his or her parents, then neither the parents or the "caretaker's" income is counted. For example, if the child is living with an uncle and aunt, the uncle's and aunt's income will not be considered available to the child. The parent's income is not counted because the parents are not in the home.

Child support is considered the child's income.

The family's resources are not counted in the Poverty Level program for children.

Income Levels for child(ren) under age 18

Household Size	Monthly Net Income Limit
1	$ 988.00
2	$1,337.00
3	$1,685.00
4	$2,034.00
5	$2,382.00
6	$2,731.00

For the following programs, the household's resources (assets) are counted.

Children's Medical Assistance (CH), for children born after 9/30/83 and under age 19

This program includes Medicaid In and Out Assistance for children who are older and the family is over income for assistance under another category.

Medicaid In and Out is a program for families who have too much income to qualify for regular Medicaid, but whose medical bills exceed their ability to pay in any given month. Depending on the household income, the family will be responsible for a certain amount of medical bills each month (called the "spend down"), and then Medicaid will pay for expenses over and above that amount. The family's resources (assets) are counted and must be under state resource limits.

Children's Medical Assistance CH-INCOME LEVELS FOR 1994: Household Size-	PIL
1	$460
2	$642
3	$652
4	$662
5	$673
6	$754

C. Medicaid only for Children With Severe Disabilities

To qualify for Medicaid in this program,

• The child must be under age 18, or 18 and still in school. (Many youth age 18 qualify for APTD which does not count parent's income).

• The child does not have to be in a home where there is some "deprivation" (such as single parent, etc.)

• The parents' income and resources are deemed to the child, in other words, some of the parents' income and resources are counted

• The income and resources must be under the same income levels as for the CH program (see above).

• The child must have a severe disability, meeting medical eligibility criteria such as a severe long-term medical condition, a severe developmental impairment, etc.

In practice, if the child was born on or after October 1, 1983, it may be easier for the child to qualify under the income levels rather than trying to prove long term disability. The worker at the Division of Human Services can help the family to figure this out.

In addition, if the family has medical bills which are high, the child may qualify for In and Out Medicaid, even if its for only one month. There is no "ceiling" on family income for In and Out, as long as the child meets all the other program requirements, the family's assets meet the requirement, and the family's medical bills are high.

SUMMARY OF PROGRAMS FOR CHILDREN IN LOW INCOME FAMILIES:

• In a very low income household, single-parent family, etc. the child and parents may qualify for **Financial and Medical Assistance.**

• In a family with net income under "170%" of the poverty level, the child(ren) born after September 30, 1983 may qualify for Medicaid only. Parents' resources do not count. (Current proposals in the 1994 legislature may change these levels to 185% of poverty for all kids under age 18-check with the local DHS office for the newest income levels).

• In a family with resources under the state limits for Medical Assistance, the children born after 9/30/83 and under age 19 can receive In and Out Medical Assistance (CH).

Medicaid Example-Low Income Levels

Sharon and John D. have three children. Their oldest child is ten (born on January 10, 1983) and they have twins born on September 5, 1992. The twins appear to have developmental impairments. John earns $1,400 per month (gross) as a welder, and Sharon stays home. Sharon applies for Medicaid for all of her children. ***The twins are eligible for Medicaid, whether or not they have a disability, because they were born after 9/30/83 and the family's income is low enough for children in the low-income category.*** *The ten year old child is too old to qualify under the current rules and so is not eligible for Medicaid.*

D. Home Care for Children with Severe Disabilities (Regardless of Parents' Income)-"Katie Beckett"

Home Care for Children With Severe Disabilities (HC-CSD) is a special Medicaid category designed to encourage families to keep the child who has extensive care needs at home. These children receive Medicaid regardless of the family's income. **For HC-CSD the parents' income and resources are not counted. Any resources or income which can be attributed to the child do count (such as a trust for the child).**

Many families have come to call this the **Katie Beckett** program, referring to one of the first children to demonstrate the need for this program. The parents' income and resources are not counted to determine income eligibility. Proof that the child needs an intensive level care of care is the major requirement for this eligibility category.

To qualify for Medicaid under Katie Beckett rules:

• The child must be under age 18, or 18 and still in secondary school.

• The child must need the level of care one would get in a hospital, nursing home, or other skilled facility.

• It is medically appropriate for the child to stay at home.

• It is less expensive to keep the child at home.

• The **child's gross monthly income,** with nothing subtracted, cannot be more than $1,127. The **child's resources** must be under $2,500.

• The child must be living with at least one parent.

The key to getting Medicaid under this category is to prove that the child needs nursing care at a level that would normally result in institutionalization were the child not at home. This means that the parent must be providing support and services to the child. The parents must fill out forms about the level and intensity of care they give their child. If the child requires much care from the parents to function at home, the parents must make sure they write that down on the forms.
Note: The rules about eligibility for Katie Beckett are being reviewed and revised during 1994.

The importance of HC-CSD (Katie Beckett):

Many lower- or middle-income families have children with severe disabilities and income too high to qualify for Medicaid under the groups described previously. These families may or may not have health insurance such as Blue Cross/Blue Shield, an HMO, etc. through their employer. Few insurance plans will cover the daily habilitative and rehabilitation needs of the child with chronic multiple medical and/or behavioral issues. Many families cannot afford the cost of equipment, care and therapies needed for their child even if they have private health insurance.

The Medicaid program, according to federal and state law, must pay for certain medical, therapeutic, and rehabilitation services for which other insurers and families may not be able to pay. If a child needs intensive and frequent medical care in the home, the family should apply for Medicaid under the HC-CSD option, regardless of that family's income. The Katie Beckett rules state that the child may have a medical condition, developmental disability, emotional disorder, etc. and qualify for Medicaid under these special rules. Many families have had success obtaining Medicaid for their child by documenting all the "little things" the parents must do to help their child function in the home. The Medicaid program may be the key to getting the support needed to keep the family functioning and together.

Medicaid Example- Katie Beckett

Emily and Roger P. have two children. The oldest child is seven and just entering first grade. The younger child, Henry, is four and was diagnosed at birth with Spina Bifida. Henry is not yet able to walk or crawl, and requires a special chair in order to sit. Henry cannot yet feed himself, and requires special food preparation. Henry verbalizes but does not yet speak. Henry's eyesight and hearing are adequate. Roger is a lawyer with a successful practice in New London. Henry's medical bills, however, are continually high and tax the family's resources. Emily and Roger apply for Medicaid for Henry under the Katie Beckett rules. Even though the family is considered over income, Henry's daily care needs are such that he is accepted for Medicaid. The family works with their regional Family Support Coordinator and their local school district and builds a program for Henry which includes home nursing support two hour per week, two days per week in a pre school program, and limited speech and language therapy. The nursing support, some components of the pre-school program, and speech therapy are Medicaid-billable. The school pays for Henry's pre-school tuition, and the Family Support staff provide respite to the family once every six weeks. The family is thus able to cope well with the demands of caring for Henry.

MEDICAID FOR ADULTS (18 YEARS OLD OR OLDER)

When a child turns 18 years old (19 if still in school), the child is now an adult for the Medicaid program. This means that:

• The parent's income is no longer considered available to the child.

• The parent's resources are no longer counted.

• If the youth is able to work and does not have a disability, that person will no longer qualify for Medicaid. For example, the child in a low income household who does not have a disability will receive medicaid, but only until that child turns 18 years old (19 if still in school).

• An adult with a disability is judged against state disability rules for adults. These rules use the same disability standard as for SSI eligibility.

• If the adult has a disability, that adult must also have income below state income levels. For more information on adult benefits, see "Basic Benefits Planning Guide for New Hampshire, 1994".

• If the adult has a disability and is under the resource limits but over the monthly income limits, that adult can receive Medicaid In and Out.

•Adults and children with blindness or a severe vision impairment, and who meet certain income criteria can qualify for **Aid to the Needy Blind-ANB.**

FOR YOUNG PEOPLE WHO EXPERIENCE DISABILITY TRANSITIONING OUT OF SCHOOL AND INTO ADULT LIFE:

A youth may not have been able to get Medicaid as a person under age 18 because of the parents income. That same youth may qualify for Medicaid as an adult with a disability at age 18.

F. Other Medicaid Groups

There are two special groups of children who get Medicaid because of their living situations: **Children in Foster Care and Children Receiving Adoption Subsidy.**

Children in Foster Care are children who live in a variety of settings outside of their parents' home. This includes state supported foster homes, group homes, institutions under the supervision of the Division of Children and Youth, homes with relatives other than parents, etc. **These children usually receive Medicaid.**

Children in Subsidized Adoption situations are those where the child has a special need, including a developmental disability, learning disability, a disadvantaged background, and a chronic medical condition, etc. **The adopted child may receive Medicaid** in these situations.

What Medicaid Pays For

Medicaid is more than a health insurance plan. In addition to the usual medical and therapeutic services people associate with health insurance, Medicaid covers all medically necessary services as outlined in the state's medicaid plan for children under age 18, under CHAP for children under 21, and includes special programs for eligible adults with disabilities. Many of these programs are in the Program Section of this manual.

Medicaid-reimbursable Medical Services are listed here. Individuals who are eligible for Medicaid do not have to get approval from Medicaid to get these services. There are caps and limits, however, on the number of units of and scope and intensity of service a person can get in each category each year.

- •Doctor's services, psychiatrist services, oste-opathy services, and Advanced RN Practitioners at a clinic, office, outpatient unit, etc.
- •Hospital Inpatient treatment and care (medically necessary)
- •X-Ray services for diagnostic purposes
- •Outpatient hospital visits
- •Outpatient Rehabilitation Services
- •Foot Doctor services
- •Psychologist
- •Chiropractor

•Optometrist services

•Community Mental Health Services

•Prescription drugs - free for children under age 18

•Transportation - as required to get to a medical service

•Dental services-under $450
NOTE:
CAPS and limits on services may be removed for children and youth (up to age 21) in an approved CHAP (EPSDT) treatment plan.

Before you get the following services paid by Medicaid, the doctor or other provider must get approval **ahead of time**:

- •Out of state hospitalization
- •Private Duty Nursing
- •"Durable" medical equipment including wheelchairs, beds, etc.
- •Adult Medical Day Care
- •Organ transplant
- •Certain Dental services
- •Nursing Facility Care
- •Orthopedic shoes
- •Hearing Services

Other programs and services covered by Medicaid available to all children:

- •Early Intervention services - ages birth to 3
- •Speech and Language therapy - any age
- •Therapeutic day care
- •Life sustaining nutritional services
- •Hearing, Audiological services-any age (Prior approval required)
- •Physical therapy
- •Early Periodic Screening, Diagnosis and Treatment Services (EPSDT), Known as **CHAP** in New Hampshire- under age 21
- •**Any medically necessary treatment services** which have been pre-approved by the Medic aid office as a result of a CHAP screening.
- •Therapeutic day and residential services (for non-school age adults who have developmental disabilities or mental illness)
- •Public health clinics
- •Home Care for People with Chronic Medical Conditions - known as HCBC in New Hampshire
- •Certain medically - related services outlined in the Individualized Education Plan as pro vided by the child's school system

Child Health Assurance Program (CHAP)

CHAP (also known as Early Periodic Screening, Diagnosis and Treatment or EPSDT) is part of the Medicaid program for Medicaid-eligible children and youth up to age 21. Every child who gets Medicaid is automatically eligible for CHAP. The law says that every family should be informed about CHAP when the child gets Medicaid. CHAP means that every child should get a comprehensive health and developmental exam on a regular basis (schedule depends on the child's age) and Medicaid will pay for it. This exam can be done by any doctor enrolled in the Medicaid program.

What makes CHAP important is:

• The CHAP screen should be comprehensive. Although a General Practitioner will usually provide the screen, that doctor may recommend additional screening by specialists which can include a Psychiatrist, psychologist, etc..

•**Any medically necessary service needed as a result of the condition found in the CHAP screen should be treated and covered by Medicaid.** The Division of Human Services must pre-approve any recommended treatment or lift on caps which are not usually covered by Medicaid.

• The course of treatment recommended as a result of the screen can be outside of the usual services covered by the New Hampshire Medicaid program. The treatment must be proven to be medically necessary and services outside the usual scope of Medicaid must be approved ahead of time by the Medicaid Office of Medical Services (OMS).

• The treatment should be comprehensive. The law states that the treatment should be designed to remove or reduce the effects of the person's medical condition, if possible.

HOW CHAP WORKS:

Every child who is eligible for Medicaid is eligible for CHAP. Each Division of Human Services office has a CHAP representative who can explain the program to the family. In a couple of regions, clinics have been set up to provide comprehensive screenings and other services for children and adults, and this model may be replicated in other regions. There is a recommended schedule for exams (CHAP screenings) according to the child's age. The provider of service must be a enrolled as a Medicaid provider.

NOT ALL DOCTORS KNOW ABOUT CHAP. The Division of Human Services CHAP representative, the Family Support staff, statewide Family Support Coordinator, or Case Manager can help a family or Physician understand more about CHAP.

STEP 1: THE FULL CHAP SCREEN:

•Medical history and exam appropriate to the child's age
•Developmental assessment

•Vision and hearing screening

•Nutritional screening

•Dental services

•Immunization check

•Further screenings as indicated by the initial assessment

A child may have a partial screening.

When a child has a CHAP exam, the doctor should discuss the child's condition(s) with the family. The family and service coordinator, as appropriate, need to work with the doctor to make recommendations for services which are "medically necessary" and will address the child's condition. The doctor is not limited to making recommendations for routine medical treatment.

STEP 2: THE CARE PLAN

In order for follow up services to the CHAP screen to be covered by Medicaid, a written care plan must be submitted to the Office of Medical Services. A physician (or psychiatrist, ARNP, psychologist or associate psychologist) must agree with the plan. The plan must document the medical necessity of the treatment. The request must include:

- •A diagnosis
- •Description of what will happen if the child does not receive the service
- •The medical need
- •Expected outcome and timetable
- •Historical medical data related to this treatment
- •List of agencies and providers to which the child is being referred
- •Assurance that the treatment is the least restrictive/cost effective service

Families should seek help from a family support staff member, a case manager, etc. to develop the care plan in cooperation with the physician. A new program, **CHAP PLUS** includes all the CHAP services listed above, plus **case coordination** for parents who have no source of help to use the CHAP services effectively.

THE CHAP SERVICES:

•dental services

•therapy, physical, occupational, speech and hearing

•needed equipment, durable and non-durable

•programs, such as early intervention services

•Community Mental Health services, even when those services are provided outside the school.

•and any other treatment which is **medically necessary and needed to improve or cure that child's condition.**

CHAP EXAMPLES

A two year old child has Down Syndrome and developmental delay. The doctor recommends physical therapy for five hours per week, and an integrated day care setting with related therapeutic services for the child. If the DHS approves of the plan, Medicaid will pay for the therapies because they are medically necessary.

In another example, a doctor recommends the purchase of equipment and mobility instruction to help a thirteen year old child with visual impairment and learning disability to get the most out of regular classroom instruction. If the school district is a Medicaid provider school, that school can bill Medicaid for the services. The school will pay half of the cost and Medicaid will pay the other half. If the equipment cannot be purchased by the school, it can be purchased through the recommendation of the doctor after a CHAP screen, as long as the equipment is medically necessary and the family goes through the prior authorization process.

CHAP needs to be managed by parents and advocates:

• **The parents and advocates need to work with doctors** and let them know that CHAP screenings are paid for at a higher rate by Medicaid than other exams.

• The doctor needs to know that **limits on services may be removed** when a course of treatment is developed as a result of the CHAP screen. Many services have an annual maximum over which Medicaid will not reimburse. The CHAP can remove limits for services if approved by the state ahead of time.

• **Prior approval** may be needed from Medicaid for treatment services not normally covered. The spirit of the program is to help children who get Medicaid by providing necessary medical treatment. For information about CHAP from the Division of Human Service central office.

How to Apply for Medicaid

To apply for Medicaid, the parent, guardian, caretaker, relative, etc. must go to the New Hampshire Division of Human Services office in their district. *(see Appendix)* The applicant will sit down with a Case Technician who will see if the family's income and resources are below the limits. There will be several forms to fill out. There is one form, The Children With Severe Disabilities/Report of Parent/Guardian Form (see example in the Appendix) that parents are asked to complete. The parents should offer as much information as possible about the agencies serving the child and what they feel the child needs. Under the Medical/Social information section of the form, the parents need to make sure they describe all that they do for their child. The family may complete the forms at home, and should seek help from a Family Support Worker, Case Manager, agency staff, etc. The family's assessment of the child's disabling condition is an important factor in the decision making process.

The family member will be asked about all of their income, and the Case Technician will ask for pay stubs, etc., all of the household bills, Social security numbers, birth certificates, marriage certificate and, if applying for disability status under CSD or HC-CSD, medical information about the child(ren).

The way the family fills out the forms becomes critical to get Medicaid under CSD or HC-CSD. The parents report of the child's functioning must show that the child needs support and care. The doctor must be sure to paint a true picture of the child's limitations. A doctor who never sees the child judges the medical evidence, so **make sure the information is complete.**

Parents of children with severe behavior or emotional disorders should be prepared to detail the extent of their child's condition. If the family is using a psychologist, psychiatrist, or other type of therapist, the family should seek their help with the documentation.

How Medicaid works

Once an individual is found eligible for Medicaid, they receive a letter of acceptance and later, a green Medicaid card. The Division of Human Services *must make a decision on each case within 45 days of application for all AFDC related Medical Assistance cases. Adults with disabilities must be notified within 90 days.* Medicaid coverage can go back to three months prior to date of

application if the person was eligible during those months. Eligibility is on a month to month basis and can be retroactive for up to three months if the individual qualifies. If the applicant comes into money in a particular month, that person may lose Medicaid until their resources drop again.

Medicaid may also pay for an individual's Medicare Part A or Part B premium. The family should talk to the Case Technician about payment for any Medicare premiums.

The doctor or provider must be enrolled as a Medicaid provider before services are given or Medicaid will not pay the bill. The doctor is then reimbursed by Medicaid for providing the service to the Medicaid recipient. This is after all other sources of payment have been made (such as private insurance or Medicare). The Medicaid card must be presented to the provider. Not all doctors and providers are enrolled in the Medicaid program.

Limits: Generally, half of the Medicaid money comes from the federal government, half comes from non-federal sources, including state, county and other funds. Every year the state tells the federal government what it will allow Medicaid to cover (this is done in the NH Medicaid Plan). This plan shows what the service limits will be, including limits on the numbers of units of service a person can receive in a year, limits on how much doctors and other providers will be paid, (called **rates**), and special sets of services to targeted populations (called **waivers**).

Prior approval means that the doctor or agency providing the service will not get paid by Medicaid unless the service has been authorized ahead of time. Authorization is made by the staff at the New Hampshire Division of Human services, Office of Medical services, 6 Hazen Drive, Concord, NH 03301-6521.

The Limitations of Medicaid

• The applicant must apply for Social Security and any other benefits for which they may be eligible.

• The applicant (or guardian) must sign an agreement to pay back the state share of financial assistance that person has received if that person comes into money in the future. A recipient of state financial assistance **cannot inherit money without the possibility of it being taken by the state. Careful estate planning is important for anyone receiving help from the state programs..**

• Some doctors, pharmacists, providers and clinics are not enrolled as Medicaid providers.

Summary of Children's Medicaid Programs				
PROGRAM REQUIREMENT	**AGES**	**PARENTS INCOME COUNTED?**	**PARENTS RESOURCES COUNTED?**	**DISABILITY REQUIREMENT NEEDED?**
AFDC - Financial and Medicaid In and Out	0-18 years, 19 years if in school	YES	YES	NO - must meet "deprivation standard"
Poverty level medicaid	born after 9/30/83	YES	NO	NO - no "deprivation requirement"
Medicaid for children with severe disabilities	0-18, up to age 19 if still in school	YES	YES	YES
Medicaid - home care for children with severe disabilities	0-18, up to age 19 if still in school	NO	NO	YES
Aid to the Needy Blind	ALL	YES	YES	YES - visual impairment
Aid to the Permanently and Totally Disabled	18-64	NO	NO	YES

PUBLIC HEALTH
FACT SHEET

WHAT IS PUBLIC HEALTH?
The state of New Hampshire Division of Public Health operates many federally and state funded health and prevention programs for people of all ages. Public Health includes the Bureau of Special Medical Services, which can help children with specific medical conditions and diseases such as asthma, diabetes, etc. The Bureau of Maternal and Child Health promotes preventive and reproductive health care for young families, including family planning, adolescent health, lead poisoning prevention, etc. The Bureau of WIC (Women, Infants and Children) Nutrition Services operates a supplemental nutrition and health program for nutritionally at risk women and children.

HOW TO ACCESS PUBLIC HEALTH SERVICES:
Most of the state's Public Health programs and services operate out of the state Division of Public Health. The Division has several detailed informational brochures, and can hook the parent or child up with local clinics, doctors and services, when needed.

WHAT CAN PUBLIC HEALTH PROVIDE?
Some Public Health services, like WIC, require the family to be low income. Many other services do not have income requirements or services are provided on a fee for service basis. If needed, a Public Health nurse can come to the family's home and help the family sort out their needs, help the family apply for public benefits, help the child to get into programs, receive the proper service, etc. Public Health nurses work in schools and clinics. Public Health dollars also support parent support networks such as Parent to Parent.

FOR MORE INFORMATION ABOUT PUBLIC HEALTH:
Call the state Division of Public Health Services at 1-800-852-3345.

PUBLIC HEALTH PROGRAMS DEFINED

Within the New Hampshire Department of Health and Human Services is the Division of Public Health Services. Within Public Health, there is a **Bureau of Special Medical Services**. The Bureau operates special programs for children are at risk of or who have a disability or chronic illness. Most of these programs are through community- or hospital-based clinics or other medical providers. These programs serve children with one or more chronic medical conditions. There is no income requirement for most of the services. A family can apply for help directly to the Public Health office or through a doctor, social worker, therapist, etc. *(See Appendix for Public Health listing).* Families can get an excellent brochure which outlines all the Bureau's programs and services by calling Public Health at 1-800-852-3345.

PROGRAMS PROVIDED BY THE BUREAU OF MEDICAL SERVICES PEDIATRIC SPECIALTY OUTPATIENT CLINICS:

Many of the services within the Bureau are organized by the type of disability. Some of the programs of the Bureau include:

- •Cleft Lip and Palate - Ages Birth - 21
- •Cystic Fibrosis - Ages Birth - 21, monthly clinic
- •Heart - Ages Birth - 21, clinics by appointment
- •Program for Children with Neuromotor Disabilities -Ages Birth - 21,
- •Genetics-Families, clinics
- •Newborn Screening Program - All newborns
- •Child Development- Ages BIRTH - 6 for evaluation, up to age 21 if previously diagnosed, programs and clinics
- •M.I.C.E. Program (for children with multi-sensory impairments) - Ages Birth-3, services at home
- •Hearing Impaired Program - Ages Birth - 3 services at home
- •Epilepsy - Ages Birth - 21, clinics
- •Amputee - Ages Birth - 21, clinics

THE NEXT GROUP OF PROGRAMS REQUIRE THE FAMILY TO HAVE INCOME BELOW PUBLIC HEALTH GUIDELINES:

Within these programs the Public Health nurse works with family to develop an individualized program. Children with these medical conditions may be eligible for financial assistance:

- •Asthma - Ages Birth - 21,
- •Hearing Preservation - Ages Birth - 21,
- •Kidney - Ages Birth - 21,
- •Orthopedic - Ages Birth - 21,
- •Sight Conservation Program - Children and Adults
- •Special Needs Assistance Program - Ages 0-21, financial help

•Catastrophic Illness Program - Children and Adults, financial Assistance for people who have:

*Cancer
*Hemophilia
*Spinal Cord Injury
*End Stage Renal Disease

THE FOLLOWING PROGRAMS OFFER SPECIALTY SERVICES TO CHILDREN AND MAY INCLUDE FINANCIAL HELP IF THE FAMILY'S INCOME IS BELOW PUBLIC HEALTH GUIDELINES:

•Myelodysplasia Program - (Spina Bifida)
•Pediatric Rheumatology Program - (Arthritis)
•Diabetes Program

WHAT PUBLIC HEALTH PROGRAMS PROVIDE

To receive Public Health services, the person must fill out an application, including complete financial information. If found eligible, a public health nurse or clinic staff will collect information and help to complete a Care Plan. This plan states what the person will receive from the Bureau. The Public Health nurse can often act as the "case manager," helping the individual to get into programs and services which exist in the community, or hooking the individual up with special services through clinics, hospitals, etc.

Each of the specialty care programs include:

- case coordination services.
- diagnostic and evaluation services unless evaluation is not needed.
- help for family members with training, guidance and support on how to care for the person with a disability
- help families apply for public assistance.

The Bureau also can help with financial assistance for families who meet the income guidelines. Any services given to the family are written into the Care Plan. *It is important for families to help with the development of the Care Plan.*

Public Health can fill in the service gaps for a child with a disability. For example, if a parent needs to get the child to a clinic but cannot afford to travel there, the Bureau may be able to help with transportation money. In another example, the teachers at school do not feel comfortable dealing with a child's medical needs, so the public health nurse becomes a part of the education team and works with the school staff. Using the Care Plan is the key to getting what is needed.

OTHER SERVICES FUNDED BY THE DIVISION OF PUBLIC HEALTH

In an effort to support children and adults with disabilities, Public Health provides funding to Parent to Parent, a statewide peer support organization for parents of children with disability. The Bureau also provides education and training to school districts. The Bureau can give financial assistance to children or adults who cannot get Medicaid because they do not meet the New Hampshire definition of disability. The Bureau can sometimes help a person to buy a piece of equipment, a prosthetic devices or even glasses for the person who has no other source of funding.

SOURCES:

N. H. Department of Health and Human Services, Office of Medical Services, Public and Medical Assistance Manual, He-W Chapter 500, Revised 1992.

N. H. Department of Health and Human Services, Division of Public Health, Circular, "Bureau of Special Medical Services"

PRIVATE HEALTH INSURANCE FACT SHEET

WHAT IS PRIVATE HEALTH INSURANCE?

Individuals and groups pay a flat fee for coverage through a health insurance plan from private, quasi-public and public entities which cover the cost of the covered individual's medical bills. Insurance companies are regulated through the state's Department of Insurance. Health Maintenance Organizations (HMO's) are also insurers. Most people receive health insurance through their employer as an employee benefit or through a professional or trade group. The cost of buying health insurance as an individual is too great for most people.

WHAT IS PROVIDED BY PRIVATE HEALTH INSURANCE?

There are as many different types of plans as there are groups and companies. Generally, health insurance does not cover the costs of long term, "chronic" conditions. Most children are privately insured as dependents on their parent's insurance policy. While care for long-term chronic conditions is not the main purpose of health insurance. Many plans do provide such coverage, especially when it involves a child.

HOW TO FIND OUT MORE ABOUT PRIVATE HEALTH INSURANCE:

For questions about state insurance requirements and rules, call the Department of Insurance at 1-800-952-3416 or 271-2261. Information about insurance is also available from the area agency Family Support staff or state Family Support Coordinator, Legal Assistance staff, the NH Disability Rights Center, Parent to Parent, the Office of Public Guardian, the Parent Information Center, and the Alliance for the Mentally Ill of New Hampshire.

PRIVATE HEALTH INSURANCE DEFINED:

Health insurance is coverage for health costs provided to people as individuals or through groups, usually through a person's employer. For children, the insurance is usually part of a family's coverage with the child as a dependent. Insurance traditionally pays for "acute" medical problems, such as short illness or diseases. In general, insurance policies are not intended to help people with permanent conditions to enhance their lives (Simon, 1993).

There are several types of health insurance programs:

• **Blue Cross and Blue Shield** - This insurer collects premiums and pays for services. BC/BS pays the provider directly for services and **cannot turn anyone down for coverage.**

•**Commercial Insurance companies** - These companies sell individual and employer health insurance plans and can choose what to cover and what not to cover.

•**Health Maintenance Organizations (HMOs)** - People join the HMO by paying a fee, and service cost is limited to a set amount per person per month. Usually, the member has limited choice of doctors and other providers, with one doctor assigned to the person's case to keep treatment and costs in check.

•**Self-Insured, Multiple Employer and Preferred Provider Plans** - These programs vary from employer to employer because there are fewer federal and state regulations governing them.

HOW HEALTH INSURANCE RELATES TO PEOPLE WITH DISABILITIES:

State laws require the health insurance companies to cover certain costs and situations. For example, in New Hampshire:

• Dependent children with a disability must get continued coverage from an insurer until the child reaches age 18. As a result, the carrier cannot drop the child from the plan before age 18. To get coverage after age 18, the child's disability must have started before age 19. In that situation, the "child" can stay on the family's plan as long as the child's disability continues and the child remains dependent on the insured parents.

• Treatment for mental illness and emotional disorders must be included as a covered service, although most policies impose low annual and lifetime coverage limits.

• If the insured leaves a job, the same continued coverage must be offered to the person at the person's expense for a limited period of time (COBRA).

• A person with a total disability must also have extended coverage after group coverage is discontinued.
• When a covered person also has Medicaid, the private insurance usually pays first, then Medicaid pays last.

Health insurers do not automatically cover costs related to treating a person with a long term disability. People with disabilities are kept out of health insurance plans in the following ways:

• Clauses related to **Medical Necessity** - Often the services and treatment needed to help a child with a disability are not consistent with standards which say that only medically necessary treatment will be covered. People with disabilities often have conditions which will always exist or will occur over and over again. Health insurance plans usually cover conditions which will gone after medical treatment.

• Health insurers often will not cover **Preexisting Conditions** - Some conditions are not covered for the first few months of the policy, or are excluded completely from coverage.

• Some plans require a particular doctor or type of professional to **evaluate** the condition before treatment can be covered. Make sure you follow your plan's requirements for evaluation or the cost of the treatment may not be covered.

• Also, there are different requirements for **prior authorization** depending on the type of plan. Some services are not covered unless you get permission first.

• There are limits on units of service, or **caps**, depending on the type of service. A prime example is psychiatric or mental health services which often have annual and lifetime caps.

HOW TO MANAGE HEALTH INSURANCE FOR YOUR CHILD:

If your family has private health insurance, you will want to carefully go through your plan and determine:
• what **long term conditions**, if any are covered by the plan.
• limits, if any, on **dependent benefits**
• caps and limits on **service units or per person costs**
• whether the plan has **"managed health care"** coverage. Managed health care may allow the insured to have contact with a case manager through the insurer. The insured person can work with the case manager to keep health costs down.
• what types of **preexisting condition limits** are on the plan.
• what type of **prior approval requirements** are in the plan.

WHAT FAMILIES SHOULD BE GETTING FOR THEIR CHILDREN WITH DISABILITIES:

The biggest difference between the needs of children with disabilities and the common provisions of health insurance is that disabling conditions are long term and health insurers seek to cover short term conditions. That is also what makes Medicaid different from health insurance. If a child is born with Spina Bifida (a genetic spinal disorder), then typical health insurance will cover costs related to the post partum medical care for the baby. The insurance may not cover costs related to a special bed for the home, home care, developmental stimulation for the child, etc.

The key to getting a service covered is whether the service is or is not **medically necessary**. Parents and doctors must work together to ensure that the family is receiving the services as outlined in the insurance plan. If the bed, home care, etc., is as medically necessary, then the insurer may cover the cost. If not, the family may look to Medicaid to cover the cost of needed services not covered by the family's insurance plan.

When there is a problem with health insurance coverage, the family should first try to resolve it with a representative of the insurance company. They need to write down the date and name of the person they spoke with. If there is still a problem, a family support counselor or other service agent can help the family go through their policy and pursue a complaint with the insurance company. If there is still a problem, the family can file a complaint with the NH Insurance Commission. The Commission employs Hearings Officers who investigate complaints about unfair insurance practices.

SOURCES:

Simon, Mitchell, Assistive Technology Manual, Institute on Disability, Durham, NH, 1993.

3. PROGRAMS and SERVICES by AGE GROUP

INTRODUCTION

Programs and services differ from individual resources in several ways. First, the recipient receives and uses an individual resource. The recipient controls the use of an individual resource. By contrast, programs and services are available to individuals who meet certain eligibility criteria. The recipient must use the services and programs in a certain way to continue to get the help.

A program is often a group of services set up in a particular order with a beginning, middle and end. **In the field of services provided to people with disabilities, we are moving away from predetermined "programs" which are designed to meet the needs of a group of people with a similar set of circumstances.**

Services for children in Early Intervention, School and Adulthood involve a predictable process: first there is an **Evaluation;** based on the evaluation there is a **Plan** developed; and then the person receives **Services and Programs. Once the child has reached a certain plateau, the process begins again with another evaluation.** The family and the person with the disability should take an active role in every stage of the service process.

Services to Children from Birth to age 3
Early Intervention
FACT SHEET

WHAT IS FAMILY-CENTERED EARLY INTERVENTION?

Family-centered early intervention is an array of supports and services for families with a child with a disability, from birth to age three. In order to qualify, the child must have a developmental delay, be at risk for substantial developmental delay, or have an established (diagnosed) condition. Parents work with professionals, other caregivers and resources as partners in sharing information and skills. Family-centered early intervention services help families to learn more about their child's growth and development, about the day to day problems that arise in a family with a child with special needs, and about how to manage the child's behavior. The support is provided in the child's home and in community settings which the family and child use as a part of their daily life.

HOW DOES A CHILD QUALIFY FOR EARLY INTERVENTION?

The family or a professional must contact that family's developmental services area agency to apply for assistance. A person knowledgeable about early intervention services will then talk with the family and arrange for an initial evaluation and assessment, which determines eligibility. This assessment includes observation of structured play and interviews with the parents. Medical and other records are also an important part of the evaluation.

WHAT WILL A CHILD AND FAMILY RECEIVE FROM EARLY INTERVENTION?

Once a child is determined eligible for early intervention services, the team, including the parents, will develop an Individualized Family Support Plan (IFSP). This plan must be developed within 45 days of referral, unless the family finds the timeline impossible. The IFSP is a promise to the child and family that resources will be recognized and developed, concerns and priorities will be addressed, and the family's hopes will be encouraged and supported. The plan must include outcomes, methods and steps to reach the outcomes. A service coordinator (service provider) is identified. The parent may act as co-coordinator. The service coordinator is to make sure that the plan is carried out, reviewed and updated at least every six months.

HOW TO FIND OUT MORE ABOUT FAMILY CENTERED EARLY INTERVENTION SERVICES:

There is a list of regional area agencies and Early Intervention programs in the Appendix. More information is also available from the regional Family Support Coordinator, the state Family Support Coordinator or the Early Intervention Program Specialist at the New Hampshire Division of Mental Health and Developmental Services.

FAMILY-CENTERED EARLY INTERVENTION DEFINED

The state of New Hampshire has developed a regional system for helping families of children age birth to 3 who experience developmental delay, who have an established diagnosed condition or who have a condition which has a likelihood of resulting in a significant developmental delay. These services, called Family-Centered Early Intervention Services, are designed to meet the individual needs of each child and family. The "entry point" into this system is through the family's local Area Agency for Developmental Services.

Within family centered early intervention, parents and professionals, other caregivers, and resource individuals work together as partners, sharing information and skills. Early intervention services are designed to help families learn more about their child's growth and development, about the practical problems that may arise with having a child with special needs, and about how to manage their child's behavior. Support is provided in the family's home or in the community settings which the family and child use as part of their daily lives.

HOW EARLY INTERVENTION WORKS

Step 1: Referral and Assessment

The family or a referral source contacts the family's regional developmental service area agency to apply for early intervention services. A person knowledgeable about the various services and supports then talks with the family and arranges for an initial evaluation and assessment. Eligibility is determined from the results of this developmental evaluation which is conducted with the parents by qualified professionals from two or more disciplines based on the child's special needs. The assessment is carried out as structured play including several team members who observe, take notes and ask questions. Parents are asked to add to the observations of the assessment. Medical records and other evaluation reports are reviewed as part of the process.

Step 2: Planning, Service Provision and Review

Once a child is eligible for early intervention services, the evaluation and assessment team, including the parents, will design and write an Individualized Family Support Plan (IFSP), based on the child's evaluation and a family self-assessment of concerns, priorities, and resources. This must occur within 45 days of the child's referral, unless the family cannot make the timeline. The IFSP 1) recognizes the resources of the family and promises to build upon them, 2) addresses the concerns and priorities of the family, and 3) encourages and supports the family's hopes. The IFSP documents the desired outcomes and methods and identifies a service coordinator who is an early intervention service provider. For example, a speech therapist becomes the service coordinator for a child who's primary service need is speech and language therapy. Parents may become co-coordinator with the service provider. The service coordinator assures that the plan is carried out, reviewed and updated both informally as needed and formally every six months.
Early intervention services are designed to link the family up with "generic" resources in their community, such as recreation, parent support, or other resources used by local families. The services can also enable families to meet other parents of children with similar needs in order to exchange information, discuss problems, and try out solutions.

THE FAMILY'S BENEFITS AND EARLY FAMILY SUPPORT:

No family is denied services because of inability to pay. On an individual basis, many early intervention services are fundable through private health insurance and Medicaid. Also, the CHAP program within Medicaid can pay for initial and ongoing evaluations needed to develop or update the IFSP. Conditions found in the CHAP screening may pay for many of the services identified in the IFSP, including medically necessary therapies, in home services and equipment (refer to Medicaid-CHAP section).

Some private health insurance policies limit coverage for long term conditions like developmental disabilities. Each policy is different, however, so the family should carefully study its plan.

Public health services can help to fill in the gaps in an IFSP. For example, there may not be money available to pay for a piece of adaptive equipment for the child and the child qualifies for help from Public Health. The IFSP could include this resource. The family can seek help from the Early Intervention service coordinator or area agency family support worker to find out where the resources are for their child. The more the family is active in the development of the plan, the more the child will benefit.

THE RELATIONSHIP BETWEEN FAMILY SUPPORT AND EARLY INTERVENTION:

Family support services are a part of each regional area agency and are operated by local family support councils which determine how dollars can be given out for the benefit of local families. Family support services focus on enabling families to remain the primary caregiver of a child or other family member with a developmental disability. Families of children who are eligible for early intervention services may also become involved with family support services. Family support can help in many ways, including arranging for respite care, helping parents attend a related conference or training, and paying for a service or item needed in an extreme situation.

WHEN A CHILD IS ALMOST THREE YEARS OLD . . .

Not all children participating in early intervention services will need help beyond their third birthday. Some children are able to leave the system even before their second birthday. For children leaving the early intervention system, a written transition plan must be developed. For children entering the system between the ages of 24 and 36 months of age, development of a written transition plan is included in the first IFSP. For those children in need of continued service after age 3, there is a meeting with the early intervention provider, family, and local public school district, if the family approves. This meeting must take lace at least 90 days before the child turns three to review the child's service options and to develop a plan for transitioning the child from the early intervention service network over to the public school responsibility. **This transition process requires written consent from the parents for release of information to the school district.**

If the child is moving on to school district services, the school district needs planning time to accommodate the needs of each child coming into the system. The earlier the family or the family's early intervention network contacts the school, the smoother will be the transition. The special education department of the local school district will accept applications for soon-to-be three year olds. During this transition phase, the family should be told of their rights under Part B of P. L. 102-119, which covers preschool special education services. There should be a complete discussion of all the available community options for the child and the family. Families will be given help to evaluate their options and access services.

A list of Early Intervention programs, Family Support Coordinators and Area Agencies are in the Appendix.

SOURCES:

National Early Childhood Technical Assistance System, Frank Porter Graham Child Development Center, "Overview, Infants and Toddlers with Disabilities Program," Nov. 1990.

New Hampshire Interagency Coordinating Council, "Birth to Age 3," Annual Report, 1991.

Public School Services for Students with Disabilities (Ages 3-graduation, or age 21) FACT SHEET

WHAT ARE PUBLIC SCHOOL SERVICES?:

Federal laws provide that every child between age 6-18 should have a free education. The law also states that **if a child between the ages of 3-21 has a disability, that child is entitled to a "free and appropriate education" in the most normalized possible setting**. The local school districts in New Hampshire provide these educational services. Larger school districts have Special Education Departments while smaller schools handle special education services through the Supervisory Administrative Units (SAUs).

HOW DOES A CHILD QUALIFY FOR SPECIAL EDUCATION SERVICES?

The family or a professional refers a child to the child's school district through the Special Education Department or by contacting the school. The school will then gather information on the child's medical and developmental characteristics, and decide if the child has an "educational handicap." The disability requirements for special education services differ from the requirements for other entitlements and programs.

WHAT WILL A CHILD RECEIVE FROM SPECIAL EDUCATION SERVICES?

As with other programs, the type, intensity and scope of services are individualized to each child's abilities, goals and needs. The school is obligated to help the child get the most out of public education, including access, when appropriate, to regular classroom instruction and services which will help the child in school. These services include, but are not limited to, speech and language services, preschool services for young children, occupational therapies, assistive technology, psychological/behavioral services, curriculum modification, vocational training, tutoring and classroom assistance. The school works with the child and parents to form a team which develops a service plan. The school must provide for any service outlined in the plan.

HOW TO GET MORE INFORMATION ABOUT SPECIAL EDUCATION SERVICES:

The family's local school district or special education office can provide information about the school and how to begin an application. The New Hampshire Department of Education can also provide general information to families. The Institute on Disability can provide advocacy and support for families, and also can provide training and support to teachers who are working with students with disabilities in the regular classroom setting. The Parent Information Center in Concord assists families to advocate vis a vis educational services. Early intervention support staff can also assist families with young children to transition into special education services.

PUBLIC SCHOOL SERVICES FOR STUDENTS WITH DISABILITIES

The federal government requires that every child between the age of 6-18 receive an appropriate public education at no cost to the family. The federal law goes on to state that each child between the age of 3 to graduation or age 21 (whichever comes first) with an educational handicap must receive a free and appropriate education. The law places responsibility for education with each local school district. The right to a free and appropriate education for students identified as disabled is written in Public Law 94-143. This law, recently renamed the Individuals with Disabilities Education Act (IDEA), also says that children with disabilities should be educated in the most normalized setting possible, and be given the skills needed to move on to a productive adult life.

SERVICES PROVIDED BY THE PUBLIC EDUCATION SYSTEM

The law states that every child with a disability beginning at age three must have appropriate educational services available to him or her. The family with a young child with a disability must first contact the local school district to apply for services. For a child already in school or just entering school, the family, a teacher or anyone else can refer a child for evaluation. The IDEA federal law is very broad and says that any program or service which will allow the child to benefit educationally may be appropriate. The most frequent types of services include:

- Speech and Language Therapy (Communication Therapy)
- Occupational Therapy
- Physical Therapy
- Tutors,
- Psychological Services
- Special curriculum
- Pre-school and Kindergarten Programs (3-6 year olds). This can include in- home educational programs
- Equipment and modification of classroom equipment and tools
- Vocational programs
- Transition from School to Work Services
- Behavioral Training Services
- Nursing Services
- Counseling and Support Services
- Special Transportation
- Instructional Support Services

The provision and scope of services vary from school district to school district and can depend on the philosophy of the school board and the school staff. A student with a disability and his or her family needs to know the entitlements under the law. **Any student with a disability is entitled to services in the most normalized setting possible.** School districts occasionally recommend a student be "placed" in a special facility far away from their home community. The school must pay for that placement and transportation if it is what the team wants. For most students, however, the services can be provided in the regular classroom, and the school must provide the needed supports to make that happen.

HOW A STUDENT RECEIVES SPECIAL EDUCATION SERVICES

Anyone can refer a child to the school district for a special education evaluation. The standards used to judge whether or not a student is eligible are not the same as for other programs. The student must have an educational handicap which can include a learning disability, a developmental disability, an emotional disability, a physical disability, etc. The school district staff or a person hired by the school district test each student referred for special education services. Sometimes there is an evaluation by a certified psychologist or physician. A decision about the student's eligibility is then based on the results of the team meeting. A student found eligible is then identified for special education services. A standard code is assigned to each student found eligible for special education services. The code is based on the nature of the child's disability.

Medicaid can be billed by the school for certain services as part of Individualized Education Plan (IEP). These services must be medically related under the state Medicaid rules (see Medicaid section). The child must be Medicaid eligible and the school must be enrolled as a Medicaid provider in order for Medicaid to be billed for school services. There are no annual limits on services reimbursable by Medicaid within the context of a school IEP program.

THE INDIVIDUALIZED EDUCATION PLAN

The first step in serving students is the development of the **Individualized Education Plan or IEP. This is a very important part of the special education process** and it is important for students and parents to help make it work. The IEP is a written document which includes: 1) A statement about the student's disability and current performance, 2) a long term goal, 3) short term objectives (usually for the school year), 4) how those objectives will be reached, i. e. what services will be given to the student, 5) how much service the student will receive, i.e. how many hours per day or week, and, 6) how people will know if the objectives have been reached. The IEP is an agreement between the student and school district. Usually the IEP is written as the result of one or more "team meetings." The parents and student may be a part of the team and the parents must sign the IEP. The law says that the student and family should be invited to have a say in the development of the plan.

The IEP should be meaningful to the student. For example, an objective may be for a younger child to be able to say six words in response to pictures. A better objective may be to have the teacher work with the parents or the day care provider to learn new words in the context of daily living. Another example may be for an older student to be able to make a recipe without help in the home economics class. A better objective may be to state that the student will learn these skills in a variety of environments, including at home while making a meal, or on a job in a restaurant.

It is also important to understand the type of educational "track" the student is on. Some students in special education receive high school diplomas, some receive high school certificates of attendance. Certificates limit the student's choices beyond high school. Each family should make sure they are part of the planning process, with an eye on where the student is headed and what the student should be doing after graduation from high school.

Parents and students must provide direction and support to the school. The leadership must come from the student and family or the student may spend 4-6 years in high school learning tasks which

will not translate to adult life. The years in school should be used wisely and to the fullest because the school is under requirements to provide an "appropriate education in the least restrictive setting" and to prepare the student for becoming a productive adult. There are advocates who can help, through the NH Parent Information Center, the Parent to Parent Network, the Alliance for the Mentally Ill of NH, and other organizations. (see Appendix).

THE TRANSFORMATION OF SCHOOL SERVICES

The federal law requires that every student with special needs should be served in the least restrictive setting. There is difference of opinion among teachers, administrators, parents and others as to what this means. Some schools still offer "self contained classrooms" for students with special educational needs. These are classrooms which contain only students with disabilities. There are "special needs" classes designed just for students within special education. Students with disabilities ride on "special buses" even though there is no physical reason for segregation. Students with disabilities eat at other times than typical students, go to different jobs and vocational classes, go to segregated preschools, etc. Some students are sent away to residential placements because they are identified with behavioral or other severe educational disabilities.

The students and parents may not be told about are other options beyond segregated classrooms. If the family and student do not like the options as presented, they may be able to settle on an alternative: a typical setting with supports provided for the student. The law says that each student in special education should have access to the least restrictive alternative. It is a good idea to begin by imagining what type of educational services the student would receive if the student were in regular education services. Supports can then be developed around that educational program.

VOCATIONAL EDUCATION

Vocational education is a good alternative for the student who does not want to go to college and knows what he or she wants to do. Vocational Education includes technical classes related to specific occupations such as computer technology, automobile maintenance, child care, metal shop, etc. Smaller school districts usually bus students to regional vocational centers for all or part of the school day. Bigger districts may have a full vocational program in the high school. The largest districts, like Manchester, have a separate Vocational Technical center.

Access to vocational education for students with disabilities varies from region to region. The law states, however, that vocational education should be available to all students. Again, the creative IEP team will try to develop supports for the student in the typical setting. Allowances are made for students with physical or intellectual disabilities. **The vocational education programs in New Hampshire are receiving special state and federal funds earmarked for all students including students in special populations.** The vocational education staff in each district should be brought onto the IEP team to help plan for transition into vocational education classes. The student can take one or more vocational education classes. What makes vocational education classes attractive is that they relate directly to a job and can be very valuable for teaching functional skills in math, reading, etc.

Another aspect of vocational education is its connection to the business community through instructors, apprenticeships and jobs. The vocational department of each school has an advisory board made up of employers. The vocational education staff often set up apprenticeships, on the job learning situations and part time jobs. This can make a good connection for the student with a disability.

TRANSITION SERVICES

Once a student enters High School, the focus of learning shifts to what will happen after high school: i. e. college, other education, a job or other option. A student with a disability who is in high school should use the IEP planning process to develop ideas about the future after high school, and begin getting educational services which relate to reaching that goal. This is called planning for transition from school to adult life. The IDEA law says that Transition services must begin for each special education student by age 16. It is wise for parents and students to begin the process earlier.

The IDEA requires the school to take the lead to give Transition services to each special education student. The quality of the planning will depend on the leadership of the student and family. The transition services must appear in the student's IEP. Transition services are more meaningful with real input from the family and student. For example, the student should begin to ask questions about what will happen after graduation:

- Where will I be each day? At a job? At a school? Sitting home?
- Where will I be living? With whom?
- What will I have for money? Health insurance?
- What type of help will I need? Who will help me?
- How will I get around?

Transition services must include referral of the student to the agencies, schools and resources needed to help that student make a smooth transition to activities after graduation. This means that adult service agencies such as the Division of Vocational Rehabilitation, Job Training Council, the mental health center or area agency (all described in the section, To Adulthood) are part of the transition team, as appropriate. The student can use the Resource Planning Section of this guide as part of that process.

THE IMPORTANCE OF TRANSITION PLANNING

Most juniors have some idea of where they are headed after high school. Many students in special education don't have the same strong sense of direction because: 1) they leave the decisions up to others, 2) they don't always have to leave school until they are 21 and, 3) they have not had the chance to test out their skills and maturity because they have been in segregated learning environments. Early transition services can help avoid a crisis upon graduation by:

- **Identifying and seeking relevant job experiences for the special education student** - The sooner a student has work experiences, the greater the student's range of choices from which to make plans.

• **Identifying future support needs** - Upon graduation, the student in special education will not automatically have service needs met. The student may not meet adult service criteria, some adult service programs are time limited, and some serve only the people with severe, long term disability. There is no "entitlement" to services in the adult service network as there is in school services.

• **Identify future resource needs** - The need for money (a "safety net") and health insurance should be identified long before graduation.

• **Identify training needs after high school** - In many cases, post-secondary (after high school) education is expensive and paid for by the individual. (The NH Technical College system is currently working to include students with disabilities in its programs.)

• **Identify adult independence needs** - How will the student function as an adult and who will help that person on a daily basis? Looking at the question of independence from family should begin early in the transition process.

Once the student with a disability has graduated or turned 21, the school is not responsible to provide educational, transition or support services. **Students with special needs who are thinking about dropping out of school should consider this very carefully.** The student and family should let the team and school know if they disagree with a decision about when the student should leave school. Once a student with a disability is out of school, there may be little help available. The student and family may have to find out about resources, programs, etc. on their own. Students may return to school if they leave before reaching age 21 or prior to receiving a diploma.

WHO PAYS FOR ALL THESE SERVICES?

The IDEA law requires that each local school district pay for most of the special education services needed for eligible students within that district. When a student from a school district is sent elsewhere to an "out of district" placement, the home school district must pay the cost. The state offers financial assistance to local school districts on an individualized basis for "catastrophic" (high cost) individual programs.

Each student with a disability, their family, and the school staff should know about other resources which may help to build a complete individualized program, including:

• **Medicaid** - Any student who is eligible for Medicaid and who is in a school district which is a participating
Medicaid provider can allow the school to bill Medicaid for therapies, support, nursing and other medical services (see Medicaid Section) provided to that student.

• **Division of Vocational Rehabilitation (DVR)** - Any student who is eligible for DVR services may be able to receive help while still in school. DVR can help with services such as Job Development, Job Seeking Training, On the Job Training, equipment related to a job, etc.

• **Job Training Council (JTC)** - Some schools have a JTC program in the school. Other regions can reach JTC by calling the toll free number (see section on Job Training Council). Any student with a disability, 14 or older, can receive help getting a summer job or combination summer job/summer school program through JTC. Related vocational programs are also available through the JTC.

• **Mental Health Services** - Every community mental health center provides services to young people who experience a severe emotional disability. These services may be provided in cooperation with the schools. Medical insurance, Medicaid, other third party payor or private resources are used to pay for these services.

SOURCES:

U. S. Department of Education, Public Law 94-142, Education for All Handicapped Children Act, 1984.

U. S. Department of Education, P. L. 102-119 as amended, The Individuals with Disabilities Education Act Amendments of 1991.

U. S. Department of Education, Carl D. Perkins Vocational and Applied Technology Education Act, 1990.

AREA AGENCIES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES FACT SHEET

WHAT ARE AREA AGENCIES?

In the early 1980's, the state of New Hampshire began to close the state school for people with mental retardation. The state developed a plan for local communities to serve these former state school residents as well as other people with developmental disabilities. This plan divided the state into twelve "service regions." Each region established one non-profit area agency, governed by a board of directors made up of people from the community. Each area board is responsible for coordinating and ensuring services for all developmentally disabled children and adults in that agency's region. Eligible children of school age may receive support services from the area agency while they are under the responsibility of the school district. All area agencies provide case management and family support services. Either directly or through agreements with "vendors of service," each area agency provides therapeutic, medical, training, residential, vocational and other needed services.

HOW DOES A PERSON QUALIFY FOR AREA AGENCY SERVICES?

The applicant for services must have a developmental disability as defined by state regulations, or must be an infant with an established condition, developmental disability, or in an at risk category for developmental disability. Service provision for adults is not an entitlement under area agency services. An applicant may have to wait for services depending on that person's needs and availability of funds.

WHAT DO AREA AGENCIES PROVIDE?

Case management is the cornerstone of services provided to most area agency service recipients. Children age birth to 3 receive an Individualized Family Services Plan (IFSP). For most adults an Individualized Service Plan (ISP) is developed. Case managers will serve on the transition team for students in school who qualify for area agency services. The IFSP or ISP outlines a set of services depending on the individual's strengths, needs and situation. Some people function well in the community and need only case management services. Others receive vocational day services, residential placement and support, and therapies. Area agencies ensure that a full range of services is available for eligible people and that the resources are there to pay for them.

FOR MORE INFORMATION ABOUT AREA AGENCY SERVICES:

Contact the regional area agency (Listed in the Appendix), the New Hampshire Division of Mental Health and Developmental Services, the Regional Family Support Coordinator, or Early Intervention program.

AREA AGENCIES DEFINED:

The responsibility for providing services to people with developmental disabilities rests with the state. Up until the early 1970's, the major service for people with developmental disabilities was the Laconia State School. Parents, consumers and advocates decided that people should be served in their home communities. The state and local developmental disability parent and advocacy groups helped the state develop the regional area agency system. The last resident left the Laconia State School in 1991.

The state of New Hampshire is divided into twelve regions. Each region has one area agency designated as the entry point for services for people with developmental disabilities (a list of area agencies is in the appendix). These agencies serve children age birth - 6 and adults upon leaving high school. While the schools are responsible for children age 3-graduation, the area agencies may become involved with students who qualify for developmental disability services. Each area agency is a private non-profit organization run by a Board of Directors which is comprised of members of the community. The area boards decide policy and the scope and delivery of services to eligible people within their region. The state of New Hampshire contracts with each area board annually to provide services within certain guidelines. The way services are delivered varies greatly from region to region.

HOW A PERSON GETS INTO AREA AGENCY SERVICES:

A child age birth to three who experiences a developmental disability or is in a high risk category for experiencing a developmental disability (see section on Early Intervention) may receive area agency services. Youth and adults must have a developmental disability, as defined by the state of New Hampshire as follows:

> . . . a disability which is a result of "mental retardation, cerebral palsy, epilepsy, autism, or a specific learning disability," or is closely related to mental retardation, which results is an impairment of intellectual ability or needs "a treatment similar to" that required for people with mental retardation, and,
>
> . . . which started before the person reaches age 22, "has continued or can be expected to continue indefinitely," and poses a severe handicap to the person's ability "to function normally in society."

There are no financial eligibility requirements to enter area agency services. There is no cost to the adult receiving services from the area agency. There has occasionally been a waiting list , however, because there are not enough state dollars to serve everyone.

SERVICES PROVIDED BY THE AREA AGENCIES:

The regions differ from one another in the way certain services are offered. Every region provides case management for most of the individuals served. The Case Manager is the person who coordinates all the services, makes sure the Individualized Service Plan (ISP) is written, and makes sure the person receives the needed services. Some people who live independently and who function well in the community may receive case management services and nothing else. Other services available in every region include:

- Family-Centered Early Intervention
- Family Support
- Residential Services - Supported Independent Living, Enhanced Family Care, etc.
- Financial management - Application for public assistance
- Vocational Programs - Community Based Supported Employ ment, Competitive Employ ment, Job Placement, On the Job Support and Training
- Community Skills Instruction
- Support services such as budgeting, banking, etc.
- Therapeutic Services
- Transportation

Some regions have sheltered employment, agency-owned businesses, nursing home type residences, and other tradition therapeutic programs. Other regions have mostly community-based employment services, small residential units, and no facility based programs in the traditional sense. These differences can occur because the local area boards decide what will be provided in that region.

All area agencies employ the case managers. Some area agencies provide day, vocational and residential services directly. Other regions contract with private "vendors" for residential and vocational services. Most regions have a combination of in-house and private vendor services.

WHAT TO EXPECT FROM AREA AGENCIES:

The area agency system provides as much or as little support as the person with a disability needs. For example, a former Laconia State School resident who has no family in the community will need the case manager to help with all major life decisions such as where to live and work, how to get benefits, keeping to a household budget, etc. Sometimes the case manager hooks the individual up with the state Office of Public Guardian, helps with crisis management and advocacy. On the other hand, a high school graduate who lives at home with a supportive family may need only limited help from the area agency about where to get vocational support and long range planning for independent living.

There is no cost to the individual or the family for most area agency services. The individual's health insurance, Medicaid or other resources pay for services when appropriate. The case managers will help people apply for Medicaid if they don't already receive it. Many services the area agency provides can be billed to Medicaid.

Once a person is accepted for area agency services, the case manager will first get to know that person and may recommend some assessments or evaluations. A team forms made up of the individual, the case manager, the family members (unless the person objects) and any other people who may be helpful to the decision making process. A Client Centered Conference ("C-3") is scheduled. The team works together to develop a plan. For most individuals, this plan is called the Individualized Service Plan (ISP). THE ISP IS A VERY IMPORTANT DOCUMENT. THE AREA AGENCY IS BOUND TO PROVIDE FOR THE PERSON ONLY THOSE SERVICES WHICH APPEAR IN THE ISP.

The ISP must 1) be signed by the client or guardian, 2) outline what will be accomplished in the next five years, the next year and who will provide services, 3) show ways to judge success or failure of the plan, and 4) be updated at least once a year.

The intent of the ISP is to make a plan which meets the needs and wants of the individual. The only way for the ISP to be meaningful is for individuals with disabilities, families and advocates to make sure that the person's wishes, spoken or unspoken, are the center of ISP.

Once the ISP is written and signed, the case manager then works to connect the person with the disability to the benefits, services and programs as stated in the ISP. The case manager also works to help the person make connections within that person's community. Every person served by the area agency system has certain rights and responsibilities regarding the process of developing and carrying out the service plan.

There are two important aspects of service provision to all people with disabilities :
1. The individualization of services - The ISP process was developed to focus on the individual's strengths, needs and goals. The process should build the most "natural" system of supports and services possible for the individual. This may mean hiring a co-worker on the job to provide support. It may also mean hiring a person to come into the person's home to provide support. This creative use of resources is limited by some current rules which the state is attempting to change when appropriate. This trend means there are more choices for the individual and the individual's family.

2. More emphasis on typical situations - Area agency services are geared to support the person in the environment of that person's choice. The focus of services has shifted to community settings such as employment in competitive businesses, placement in regular apartments, living with one's family, **etc.**

These trends show that consumers and families can have more choice and control over the development of their supports services. Along with increased control comes increased responsibility. If a highly individualized support system is developed for a particular person, it may require more by the family and consumer to keep that system in place. It will also require the development of a back up system.

HOW AREA AGENCY SERVICES END

Many people with developmental disabilities will require area agency services throughout their lifetime. Agency services may be comprehensive in the beginning, and then taper off as the person gains more independence in the community. The area agencies are follow eligible people with developmental disabilities for as long as they need services. Once accepted by the area agency, the individual is rarely "discharged" from services.

SCHOOL STUDENTS AND AREA AGENCIES

The school will often invite the area agency to participate in transition planning for a student with a developmental disability who is still in school. Area agency-funded services are not usually pro-

vided to eligible students who are still in high school. The school is responsible for funding while the student is still in school. Sometimes, however, vocational services after school hours, or a high priority residential placement is funded by one of the adult service agencies while a student is still in high school. It is important for the student, family and advocates to participate in transition planning early in the student's high school years.

FAMILY SUPPORT AND AREA AGENCIES

Each area agency for developmental services employs family support staff to help families to access services, obtain information, and deal with issues related to caring for their family member. Family support staff can help family members with early intervention services, students in school, and with the care of their adult family member. The family support worker can also serve as the family's case coordinator.

Each area agency for developmental services has a Family Support Council made up of family members of individuals with a developmental disability. These councils advise area agencies in the development, implementation and monitoring of services to families within their regions. Each council appoints a chairperson and a delegate to the State Family Support Council. The state council advises the New Hampshire Division of Mental Health and Developmental Services in matters affecting families all across the state.

The family support staff can help the family of a baby or infant to 1) identify the family's and infant's strengths and needs, 2) develop short and long range goals, 3) assist the family to connect with benefits, programs and services, and, when indicated, 4) provide resources for the family.

In some regions, family support staff work with the school-age student in transition. The family support staff may help the family of an adult with a developmental disability who needs more help at home or who needs help planning for independence. A list of the family support coordinators at each region, and the statewide Family Support Coordinator are included in the Appendix.

COMMUNITY MENTAL HEALTH SERVICES FACT SHEET

WHAT ARE COMMUNITY MENTAL HEALTH SERVICES?

The state of New Hampshire serves people with serious mental illness through a network of ten regional community mental health centers. As with the area agency system, the state is divided into mental health regions, with one private, non-profit community mental health center per region. These centers provide community based services to people of all ages who have serious mental illnesses such as schizophrenia, manic-depressive illness, serious depression, or other disorders which effect the person's ability to function. The way services are provided varies from region to region. Mental health centers serve children through both school and center-based programs. New Hampshire operates a small inpatient treatment facility for children (the Philbrook Center) and New Hampshire Hospital in Concord for adults.

HOW DOES A PERSON QUALIFY FOR COMMUNITY MENTAL HEALTH CENTER SERVICES?

Anyone may refer a person to the mental health center for help. Services are voluntary except in cases when the person is committed by court order. The state standards require that a child must have a serious emotional disorder or be at-risk of developing a serious emotional disorder in order to receive services. Although there is no income limit for eligibility, people served are billed as they would be for any regular medical service. An adult must have a serious mental illness to receive state supported services. Some mental health centers have developed services for "private pay" patients such as counseling, substance abuse clinics, eating disorder clinics, etc.

WHAT SERVICES DOES THE COMMUNITY MENTAL HEALTH CENTER PROVIDE?

Each center has the capacity to provide emergency services, psychiatrist's services, case management, psychotherapy, treatment services, residential services, evaluation and testing, children's services, family supports and crisis management. Every center client with a long term psychiatric disability is assigned a case manager and has an Individualized Service Plan. The centers will also serve students in school who are eligible under mental health center guidelines. These students often receive counselling, family support, case management and transition services. **The Alliance for the Mentally Ill (AMI) of New Hampshire** is a private, non-profit organization which provides support , information, and advocacy for families of persons with mental illness. Each AMI of NH is independent of the community mental health centers but usually works cooperatively with them. The community mental health network recently added Mental Illness Management Services (MIMS) to its set of services. A person identified as in need of long term mental health care can qualify for MIMS. Under this service, an individual is provided therapeutic services in that person's community, such as at home or at school. These services are designed to help the individual make more positive connections in the most typical community setting.

FOR MORE INFORMATION ABOUT COMMUNITY MENTAL HEALTH:

A list of community mental health centers is in the Appendix. There is a Children's Services Coordinator in each center. The Alliance for the Mentally Ill of New Hampshire's office in Concord can provide information about local affiliates. The state Bureau of Community Mental Health Administration can offer information about the statewide system of supports.

MENTAL HEALTH SYSTEM DEFINED:

The state of New Hampshire is responsible for services for people with mental illness, and has developed a comprehensive community based system of publicly funded mental health services. There are also many private therapists, doctors, clinics and hospitals which serve people with emotional disabilities or mental illness, but they are not described here.

New Hampshire is divided into ten community mental health regions. In each region there is one community mental health center agency which is the entry point for all services for that region. The mental health centers are private, non-profit agencies contracted by the state Bureau of Community Mental Health Administration to provide a basic set of services to eligible clients. This community based service network has allowed the state to close the old state hospital and reduce the number of new state hospital beds to under 200. There is no age limit and no income requirement for community mental health center services.

HOW A PERSON QUALIFIES FOR MENTAL HEALTH CENTER SERVICES

The state's definition of eligibility is different for children (under age 18) than for adults.

A **child** must be:

1. Seriously emotionally disturbed (SED) - This means that the child has been diagnosed consistent with established categories of emotional disturbance, and the child has a "serious psycho-social dysfunction." *or*,

2. The child shows enough dysfunction and need for support to be considered at-risk, even without a diagnosis.

An **adult** (18 years or older) must be:

A person with a diagnosed mental illness, who needs services on a consistent or intermittent basis in to maintain stability. Some people with the diagnosis of "borderline personality disorder" are eligible if they have impaired functioning.

Many people are brought to the attention of the mental health center at a time of crisis. Some mental health centers have established programs with local schools to help children and youth who need special intervention services.

SERVICES PROVIDED BY THE MENTAL HEALTH SYSTEM:

All mental health centers employ psychiatrists who evaluate, diagnose and oversee treatment. Medication is often recommended. Most people are assigned a case manager, who connects the individual with services in the community and in and the center. The case manager is responsible for

assisting the client and physician to write an Individualized Service Plan. As with area agencies, the way services are delivered varies from region to region.

Most children and families will receive "outpatient" care through the mental health center, such as counseling once or twice a week. Children and adolescents may receive intensive individualized supports through their case manager. All mental health centers serve children through after school programs. All community mental health centers provide:

- Case management
- 24 hour emergency services
- psychotherapy- group, family and individual
- screening and periodic review
- administration and monitoring of medication
- service coordination, including helping to apply for public assistance
- psychological testing
- partial hospitalization (day program)
- crisis management - including brief hospitalization in local facilities
- recreational activities
- "other treatment services"
- residential services
- intensive after school programs

MENTAL HEALTH CENTER SERVICES AND BENEFITS:

Clients are responsible for many of the medical costs associated with treatment. Most centers have established a "sliding fee scale," and there may be room to negotiate fees. Many of the services are reimbursable by Medicaid and Medicare. Other health insurers differ on what is reimbursable. If a child has a serious emotional disability which is putting an emotional and financial strain on the family that family should seek advice from the mental health center about their benefits. The child who has a very severe emotional disability may qualify for Medicaid under the Katie Beckett rules. The Medicaid-eligible student who needs a psychiatric or psychological evaluation may be able to receive that evaluation reimbursable as part of a CHAP screen (see Medicaid section). If a person has Medicaid and is in need of "long term care," that person can receive extensive day and residential services through the Medicaid program.

If a child on Medicaid has a CHAP screen which identifies a serious emotional disorder, then the treatment plan can include community mental health center services, including intensive services. Family members of a child with a serious emotional disorder should make sure that the school team includes the mental health center case manager or other person familiar with CHAP and Medicaid (such as a family support staff member). This will ensure the child receives the services he or she needs.

WHAT TO EXPECT FROM THE COMMUNITY MENTAL HEALTH CENTER

A psychiatric assessment is conducted upon application to determine if the person meets the definition for eligibility. This usually consists of an interview with a social worker and a psychiatrist.

Upon acceptance, more evaluation may be conducted and an Individualized Service Plan is developed.

Most young people or children who qualify for community mental health center services will visit their case manager or social worker at the center for therapy and support. Case managers will also participate at school meetings and work with the family and other agencies, as needed. Some children are also under the Child Protective Services system because of alleged or documented child abuse and neglect. Other youth are followed by the Division of Children, Youth and Family Services (DCYFS) because they have broken the law or are at high risk. The mental health center will serve as a liaison with those other agencies.

TRENDS IN COMMUNITY MENTAL HEALTH SERVICES

Until the early-mid 1970's, most people with severe mental illness were in large institutions called state hospitals. The development of effective treatments such as drug therapies have allowed the state of New Hampshire to all close the old hospital for the seriously mentally ill. In the 1980's, the community mental health system put less emphasis on psychotherapy and more emphasis on "psycho-social rehabilitation," which assists people with mental illness to live, work, recreate and function in the community.

Serving large groups of people with mental illnesses in day programs and group homes has been challenged. As with people with developmental disabilities, the mental health field is heading toward individualized supports in the most natural settings possible. Recognizing that some people with mental illness will need to be set apart from the community at certain times, many others will benefit most from therapeutic support in their home, at work, and "over a cup of coffee." This means that family members and clients can look at more options for services when the Individual Service Plan (ISP) is being developed.

SUPPORT FOR FAMILY MEMBERS

The **Alliance for the Mentally Ill of NH (AMI of NH)** is a non-profit organization founded and guided by family members of people with serious mental illness. It is affiliated with the National Alliance for the Mentally Ill, with over 130,000 members nationwide and over 1,000 families in its NH membership. The central office of AMI of NH is in Concord, and is served by a toll free number (1-800-242 6264). There are AMI affiliates at 15 locations throughout the state offering education and support to families. AMI of NH's **Children and Adolescent Network (CAN)** especially for families of children with serious emotional disabilities. The CAN Network offers education, information, support, advocacy, and a chance for parents to meet other parents in similar situations. AMI of NH is also the state chapter for the National Federation for Children's Mental Health, and offers a wide variety of educational materials for families. AMI of NH also actively advocates for individual families and works for policy and legislative changes.

VOCATIONAL REHABILITATION SERVICES FACT SHEET

WHAT IS VOCATIONAL REHABILITATION?

The federal government authorizes every state to set up a program to help people who have a substantial "handicap to employment" receive the services they need to become employed. The Division of Vocational Rehabilitation (DVR) runs this program in New Hampshire. By applying for assistance from DVR, individuals with a disabilities will receive an individualized set of services geared to help them decide on a vocational goal, receive needed training, obtain needed assistive technology and equipment, find an appropriate job, and keep that job. Eligibility for the program ends once the person demonstrates the ability to remain employed

HOW DOES A PERSON QUALIFY FOR VOCATIONAL REHABILITATION SERVICES?

The individual with the disability or another agency or individual can refer the person to DVR by first calling the individual's local district DVR office. To qualify, the individual must have a disability which poses a barrier to employment. If there is some doubt about the disability, the DVR counselor set up an evaluation for the applicant. The criteria for disability under DVR is not the same as for other benefits or service systems, and is, in some ways, less rigid.

WHAT SERVICES DOES DVR PROVIDE?

After an individual is found eligible for DVR, that person may have a vocational evaluation first, especially if there is doubt about the individual's capability and vocational goal. The next step is usually development of a plan to help the person obtain employment, called the Individualized Written Rehabilitation Plan (IWRP). Once the plan is developed, the DVR counselor helps the individual to obtain the services, equipment and goods needed to reach the vocational goal. The DVR typically provides help to pay for college or other post-secondary education, job placement and training services, purchasing equipment, job modification, etc. DVR also operates the Services for the Blind Program.

FOR MORE INFORMATION ABOUT DVR SERVICES:

Contact the regional district office of DVR or the central office listed in the Appendix. The Granite State Independent Living Foundation (Appendix) can also provide information about Personal Care Assistance, Interpreters for people with hearing impairments, wheelchair transportation and peer counselling services.

VOCATIONAL REHABILITATION DEFINED

The federal government requires each state to set up a vocational rehabilitation program for its people with disabilities. All the rules governing these services begin with the federal Rehabilitation Act of 1973 and its Amendments. Each state has the ability to develop some of its own unique systems and programs as long as they conform to the Act. In New Hampshire the Division of Vocational Rehabilitation (DVR) operates this program. Included in the Act are the basic vocational rehabilitation programs, Independent Living Centers and Research and Training programs. This section discusses the basic vocational rehabilitation programs and independent living services.

The New Hampshire Division of Vocational Rehabilitation has six District Offices with a few additional "outposts." The goal of the program is to facilitate the employment of people with disabilities by providing resources which can purchase services, equipment and other needed material to help the individual get and keep a job.

Vocational Services are goal oriented and meant to last for a particular period. The goal is, of course, employment. The services which DVR purchases for the individual must relate to an employment outcome. The DVR services are to end once the person has met his or her goal.

HOW A PERSON QUALIFIES FOR VOCATIONAL REHABILITATION SERVICES:

To apply for DVR services, the individual must call up the local district office and ask for an appointment with a counselor. The requirements to receive services are:

1) The individual have a physical or mental disability, documented by a physician, which makes it very difficult to get and keep a job, and,

2) The individual can be expected to benefit from DVR services by becoming employed or more employable, and,

3) The individual should be presumed able to benefit from DVR services unless there is real proof to the contrary.

There is no particular diagnosis needed. The documentation for DVR eligibility does not have to be the same as for the other programs described in this booklet. The key to eligibility is there must be a proven "handicap to employment." There is no specified age limit in the DVR policies. The DVR counselor often works with students with disabilities as part of the transition team, and will sometimes pay for goods and services to "fill in the gaps" of a student's educational plan. Generally, however, the DVR services do not begin until the student leaves school.

The applicant must provide medical records which show that he or she has a disability, along with information about previous jobs, education, psychological tests, etc. DVR will pay for a medical exam if it is needed to complete the application. A decision about whether or not a person qualifies for DVR services must take no longer than 60 days.

If a person has the need for "long term supported employment," (that is, the person is going to need on the job support for a long time), that person needs a letter of commitment to provide long term supports. Typically, the area agency, mental health center or other agency will write the letter, but the requirement can be met by an approved Social Security PASS, an employer, a parent, etc.

There is no income limit to receive DVR services. The person with a disability is not required to pay for anything except any physical or technical modifications to the home, or college tuition or other college costs. Payment by individual is then based on that person's ability to pay.

SERVICES PROVIDED BY DVR

The vocational rehabilitation system is based on the individual and the individual's needs. After a person is accepted for services, an **Individualized Written Rehabilitation Plan (IWRP)** is developed. The plan states the person's occupational goal, the services which will be provided, the time frames, the provider, and the way success or failure will be judged. **As with the ISP, this is an important document. The IWRP states what DVR will purchase for the individual.** While there are budget realities, the law does not put a "cap" on how much can be spent on each person. Policies may sometimes dictate certain spending guidelines. For example, support services to someone on a job do not usually extend beyond 18 months, and must be justified at shorter intervals. Typical services purchased by DVR include:

- Assessment and Vocational Exploration
- Vocational Counseling
- Job Seeking Training
- Job Development
- Training on the Job (Job Coach)-temporary
- Reimbursement to Employer for Training
- Costs related to Education
- Equipment, supplies
- Business start up costs
- Transportation-temporary
- Job Modification

The DVR counselors provide some services themselves, particularly vocational counseling and support after job placement. DVR provides most services and goods by buying them from agencies (vendors). These vendors include private or public profit or non profit agencies which specialize in goods and services such as vocational evaluation, adaptive equipment, job development and support, education, etc.

UNIQUE ASPECTS OF THE DVR PROGRAM INCLUDE:

1. A DVR counselor can only purchase goods and services from a pre-approved vendor. If the person with a disability would like to work with a person from outside the approved list, that person will have to wait until they are approved as a vendor or find another provider.

2. There is flexibility for each individual's program. The DVR does not "contract" to provide services for groups of people, and so each Rehabilitation Plan is unique. While this is often an advantage, it can sometimes mean that decisions or rules applied unevenly to different individuals.

3. The DVR counselors have not typically become involved with school students until they are close to graduation. The student and family need to think in career terms very early in high school, and involve the DVR counselor in the transition planning process.

4. DVR services are time limited. The DVR counselor's goal is to get the individual into a stable job and then move onto the next person. People are not kept on the caseload forever.

USING DVR FLEXIBILITY TO SUIT THE INDIVIDUAL'S NEEDS

As long as a person's goal is to get a competitive job in the near future, that person has the same goal as the DVR counselor. Vocational rehabilitation services can fill in the gaps in a school program for a student who needs an after school job, or for someone who needs transportation, or if a person needs to look at vocational education after graduation. DVR can help with retraining and job placement, with equipment and job modification. It is important to remember that DVR services are built to suit the individual and the DVR system is required to consider the individual's choices.

Independent Living Services

The federal Rehabilitation Act requires that every state provide services to individuals with severe physical disabilities through Independent Living Centers. The Granite State Independent Living Foundation (GSILF) provides theses services to adults with disabilities in New Hampshire who need help with personal care, interpreters for the deaf, transportation, and related services. Currently these services are provided to adults and young people and in non-work related settings.

SOURCES:

U. S. Department of Education, Rehabilitation Services Administration, Rehabilitation Act of 1973, and amendments.

N. H. Department of Education, Division of Vocational Rehabilitation, Procedures Operations Manual, 1991.

The Governor's Commission on Disability, Client Assistance Program, "Consumer Guide to the Division of Vocational Rehabilitation in New Hampshire," 1991.

JOB TRAINING COUNCILS
FACT SHEET

WHAT IS THE JOB TRAINING COUNCIL?

The federal Job Training Partnership Act provides each state with resources to develop job training programs for adults and youth in certain "at risk" categories. In New Hampshire, the Job Training Council runs these programs through a state council, and through regional district offices. Many of these programs target groups such as single poor parents, high school drop outs, people laid off due to plant closings, etc. The services train participants for specific jobs in specific industries, and provide job placement assistance.

HOW DOES A PERSON QUALIFY FOR THE JOB TRAINING COUNCIL PROGRAMS?

The Job Training Council requires that most applicants be low income to qualify for services. Most people with disabilities qualify for JTC services as a "special" population. **Most people with disabilities will qualify regardless of income.** The entrance requirements for some programs may "screen out" some people with disabilities, so it is often helpful for a DVR or other counselor to help the youth or adult to apply for services. Youth with disabilities will often qualify for the Council's Summer Youth programs which offer summer jobs in the public sector, often combined with a classroom program. Students with disabilities should ask their special education teachers about Job Training Council programs in their school or region.

WHAT SERVICES AND PROGRAMS ARE PROVIDED BY THE JOB TRAINING COUNCIL?

Services and programs can vary from region to region. All areas of the state have Summer Youth work and academic programs. Help with adult basic education and vocational technical college costs is available through the Job Training Council. Industry-specific programs are provided in modules. The Job Training Council may help pay for an On the Job Training program with an employer.

FOR MORE INFORMATION ABOUT THE JOB TRAINING COUNCIL:

Call the statewide number a 1-800-772-7001 or talk to a DVR counsellor or high school vocational or special education teacher.

JOB TRAINING COUNCILS DEFINED

Every state has a Job Training Program, run under broad federal rules but controlled at the local community level through Private Industry Councils (PICS). The goal of the Job Training program is to enhance the skills and employability of people in "high risk" categories such as single poor parents, young school drop outs, and people with disabilities. The federal government gives each state and each Private Industry Council flexibility to build its own services. In New Hampshire, the NH Job Training Council runs this program.

HOW A PERSON QUALIFIES FOR JOB TRAINING SERVICES:

The Job Training Council considers a person with a disability as a family of one. This means that the person with a disability is not required to meet the same low income test as are people in other eligibility groups. Vocational tests are required for placement into the proper program. These tests sometimes "screen people with disabilities out" of the program they wish to enter. To avoid this, it is wise to ask a Vocational Rehabilitation Counselor or Case Manager for help when applying for Job Training services.

WHAT JOB TRAINING PROGRAMS PROVIDE:

The broad categories of required Job Training programs include:

• Programs to keep young people in school who are at risk of dropping out (In School Youth Programs)

• Programs for youth who have dropped out of high school (Out-of-School Youth Programs)

• Training programs targeted to train people to work in specific industries and businesses

• Help with tuition for certain certificate or other advanced degree programs

• Job Placement, On the Job Training and other job seeking/job keeping types of programs.

• Summer Youth employment programs- High school students who qualify work at public sector jobs and may attend some classes during the summer school recess.

• Project Partnerships - Some high schools have Job Training Council staff working directly with students to plan for and receive the services to enhance the transition from school to adult life.

HOW TO FIND OUT ABOUT JOB TRAINING PROGRAMS

Any high school student with a disability who is over the age of fourteen (14) may qualify for Job Training Council (JTC) programs. In some regions, JTC staff and programs are right in the high school. The special education or guidance staff should know about any JTC program within the high

school. Otherwise, call the state JTC number at 1-800-772-7001 for information about regional offices and programs.

SOURCES:

U. S. Department of Labor, Job Training Partnership Act, Public Law 97-300, 1983.

The Vocational Studies Center, "Helping Handicapped Students Become a Part of the Job Training Partnership Act," University of Wisconsin, Madison, 1986.

APPENDIX A

SOCIAL SECURITY DISTRICT OFFICES

Social Security Benefits, Supplemental Security Income, Medicare

GENERAL INFORMATION PHONE NUMBER: 1-800-772-1213

Nashua
130 Main St.

Nashua, NH 03060
(603) 886-7615

Concord
10 Ferry St.
Unit 332
Concord, NH 03301
224-1939

Keene
34 Mechanic St.
Keene, NH 03431
352-3487

Littleton
194 Main St.
Littleton, NH 03561
444-2946

Manchester
275 Chestnut St.
Manchester, NH 03101
666-7607

Salem
367 Main St. PO Box 1060
Haverhill, NH 01830

Portsmouth
80 Daniel St.
Portsmouth, NH 03801
433-0716

NH Bureau of Social Security Disability Determinations - *for information regarding a medical disability determination:*
271-3341

FOR HELP WITH AN SSI "ZEBLY" CASE: Mental Health Law Project;
1-800-523-0000

APPENDIX B

STATE OF NEW HAMPSHIRE
DIVISION OF HUMAN SERVICES OFFICES

Medicaid, Financial Assistance, Food Stamps, Child Health Assurance Program-CHAP

Berlin
219 Main St.
PO Box B
Berlin, NH 03570-0684
(603) 752-7800 or 800-972-6111

Claremont
17 Water St.
PO Box 870
Claremont, 03743-0870
(603) 542-9544 or 800-982-1001

Concord
40 Terrill Park Drive
Concord, NH 03301-7325
(603) 271-6201 or 800-322-1919

Conway
Route 16, Madison
PO Box 1946
Conway, NH 03818-1946
(603) 447-3841 or 800-552-4628

Keene
113 Key Rd.
PO Box 744
Keene, NH 03431-0744
(603) 357-3510 or 800-614-9700

Laconia
65 Beacon St. West
PO Box 634
Laconia, NH 03247-0634
(603) 524-4485 or 800-322-2121

Salem
154 Main St.
Salem, NH 03079-3191
(603) 893-9763

Littleton
Lisbon Rd
PO Box 260
Littleton, NH 03561-0260
(603) 444-6786 or 800-552-8959

Manchester
361 Lincoln St.
Manchester, NH 03103
(603) 668-2330

Nashua
19 Chestnut St.
PO Box 1025
Nashua, NH 03061-1025
(603) 883-7726

Portsmouth
30 Maplewood Ave.
PO Box 599
Portsmouth, NH 03802-0599
(603) 431-6180

Rochester
40 Winter St.
Rochester, NH 03867-3193
(603) 332-9120 or 800-862-5300

Dover
90 Washington St.
PO Box 459
Dover, NH 03820-0459
(603) 749-1646

STATE CENTRAL OFFICE OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES:
Client Services: 800-852-3345 or (603) 271-4238 or Public Information, (603) 271-4284

APPENDIX C

NEW HAMPSHIRE DIVISION OF PUBLIC HEALTH SERVICES- BUREAU OF SPECIAL MEDICAL SERVICES

Clinics, Special Assistance, Assistance for Children with Disabilities or Chronic Illnesses

FOR THE FOLLOWING PROGRAMS, CALL 1-800-852-3345, and the corresponding extension:

Cleft Lip and Palate Program
Extension 4513

Cystic Fibrosis Program
Extension 4513

Heart Program
Extension 4552

Program for Children with
Multiple Handicaps
Extension 4508

Genetic Services Program
Extension 4533

Child Development Program Network
Extension 4225

M. I. C. E.
Extension 4513

Epilepsy Program
Extension 4508

Asthma Program
Extension, 4675

Hearing Program
Extension 4513, 4525

Kidney Program
Extension 4675

Orthopedic Program
Extension 4675

Special Needs Assistance Program
Extension 4525

Catastrophic Illness Program
Extension 4529

Myelodysplasia Program
Extension 4513

Amputee Program
Extension 4513

THE FOLLOWING PROGRAMS ARE AT THE DARTMOUTH-HITCHCOCK MEDICAL CENTER:

Pediatric Rheumatology Program
(603) 646-7700

Diabetes Program
(603) 646-5473

Central Office of the Bureau of Special Medical Services: Hazen Drive, Concord, NH,

OTHER PUBLIC HEALTH SERVICES INCLUDE WELL CHILD CLINICS, Women, Infants and Children Program, Maternal and Child Health Services.

APPENDIX D

AREA AGENCIES FOR DEVELOPMENTAL DISABILITY SERVICES AND FAMILY SUPPORT COUNCILS

Family-Centered Early Intervention, Case Management Assistance, Adult Developmental Disability Support Services, Family Support Services-Developmental Disabilities, Information

Region I
Northern NH Mental Health and
Developmental Services
Conway, NH
(603) 447-3347
Family Support: Berlin: (603) 752-1005
Colebrook: (603) 636-1095 or 2555; Littleton: (603) 444-5358

Region II
Developmental Services of Sullivan County
Claremont, NH
(603) 542-8706
Family Support: same

Region III
Lakes Region Community Services Council
Laconia, NH
(603) 524-8811
Family Support: same

Region IV
Region IV Area Agency
Concord, NH
(603) 224-4153
Family Support: same

Region V
Monadnock Developmental Services
Keene, NH
(603) 352-1304
Family Support: (603) 876-4311

Region VI
Area Agency for Developmental Services
Merrimack, NH
(603) 882-6333
Family Support: same

Region VII
William J. Moore Regional Services, Inc.
Manchester, NH
(603) 668-5423
Family Support; (603) 645-9474

Region VIII

Portsmouth, NH
(603) 436-6111
Family Support: (603) 436-6283

Region IX
Developmental Services of Strafford Cty.
Dover, NH
(603) 749-4015
Family Support: same

Region X
Region X Community Support Services
Atkinson, NH
(603) 839-1299
Family Support: same

Region XI
Center of Hope
Conway, NH
(603) 356-6921
Family Support: same

Region XII
United Developmental Services
Hanover, NH
(603) 643-5439
Family Support: (603) 448-6311

New Hampshire Office of Community Developmental Services:
Statewide Family Support Coordinator; (603) 271-5057 or 1-800-852-3345 X-5057

APPENDIX E

NEW HAMPSHIRE
COMMUNITY MENTAL HEALTH CENTERS
Mental Health Services, Information

Region I:
Northern NH Mental Health and Developmental Services
Main office: 447-3347
Conway: 447-2211
Berlin: 752-7404
Groveton: 636-1090
Wolfeboro: 569-1884
Colebrook: 237-4955
Littleton: 444-5358

Region II
West Central Community Mental Health Services
Main office: 448-0126
Claremont: 542-2578
Lebanon: 448-1101
Newport: 863-1951

Region III
Lakes Region Mental Health Center
Main Office: 542-1100
Plymouth: 536-1118

Region IV
Central NH Mental Health Services
Main office: 228-1551
Concord: 228-9547
Henniker: 428-3336
Franklin: 934-3400
New London: 526-4280

Region V
Monadnock Family Services
Main office: 357-4400
Keene: 357-5270
Peterborough: 924-7236
Jaffrey: 924-7236
Winchester: 239-4376

Region VI
Community Council of Nashua
Main office: 889-6147

Region VII
Mental Health Center of Greater Manchester
Main office: 668-4111

Region VIII
Seacoast Mental Health Center
Main office: 431-6703
Epping: 679-2269
Exeter: 772-2710

Region IX
Strafford Guidance Center
Dover: 742-0630

Region X
Center for Life Management
Main office (Salem): 893-3548
Derry: 434-1577
Plaistow: 382-7932
Windham: 434-9937

FAMILY SUPPORT:
Alliance for the Mentally Ill of NH
Concord: 225-5359 or
toll free in NH 1-800-242-6264

APPENDIX F

EARLY INTERVENTION PROGRAMS

Services to children with disabilities ages birth to 3 and their families

Claremont
Milestones Early Intervention Program
(603)543-1291

Concord
Parent/Infant Development Program
228-2100

Conway
Wolfeboro Area Center
569-2614
and Children Unlimited
447-6356

Derry
Easter Seal Early Intervention Program
432-1945

Hanover
Early Child Family Support
643-5439

Keene
RISE Early Intervention Program
357-1395

Laconia
Lakes Region Community Health Agency
524-8444

Littleton
Littleton Early Intervention Program
444-0760

Manchester
Easter Seal Early Intervention Program
623-8863
and
The William J. Moore Center
Early Intervention Program
668-5423

Nashua
Memorial Hospital Early Intervention
883-5521, ext. #2886

Rochester
Child Development Center of Strafford Cty.
332-2848

Stratham
Richie McFarland Children's Center
778-8193

Statewide
The Family Support Coordinator
NH Division of Mental Health and
Developmental Services
1-800- 852-3345, ext. #5057 or 271-5057

APPENDIX G
SPECIAL EDUCATION SERVICES

Call your local School Administrative Unit for application and information about special educational services in your region.

New Hampshire Bureau of Special Education
Concord, NH
(603) 271-3494
Bureau of Special Education Services
271-3741

New Hampshire Educational Services for the Sensory Impaired
Services on behalf of students with visual or hearing impairments.
(603) 226-2900 TTD or voice

Assistance and advocacy for families with children in the special education system:
Parent Information Center
(603)224-7005 or 1-800-232-0986

Appendix H

NEW HAMPSHIRE DIVISION OF VOCATIONAL REHABILITATION

(Assistance with vocational training, assessment and employment for youth and adults)

Division of Vocational Rehabilitation
Bureau of Rehabilitation Services
Central Office
(603) 271-3471

DVR Regional Offices

Bureau of Blind Services
271-3537

Berlin Regional Office
752-2271

Concord Regional Office
271-2327

Keene Regional Office
357-0266

Manchester Regional Office
669-8733

Nashua Regional Office
889-6974

Portsmouth Regional Office
436-8884

CLIENT ASSISTANCE PROGRAM:
Advocacy and Mediation re: DVR
The Governor's Office for People
with Disabilities
1-800-852-3405 TDD or voice
or (603) 271-2773 TTD or voice

APPENDIX I

INDEPENDENT LIVING

Personal care services, information for people with physical disabilities

Granite State Independent Living Foundation
172 Pembroke Road
Concord, NH 03301
Voice, TTD (603) 228-9680, or 1-800-826-3700

APPENDIX J

NEW HAMPSHIRE JOB TRAINING COUNCILS

Assistance with job training and placement, tuition assistance, school-based job training and placement programs

Central Office-Concord
64B Old Suncook Road
Concord, NH 03301
1-800-772-7001 or 228-9500

APPENDIX K

NEW HAMPSHIRE LEGAL ASSISTANCE

Legal Services for low income people of all ages

Administrative Offices
15 Green Street
Concord, NH 03301
225-4700

Berlin
134 Pleasant Street
Berlin, NH 03570
752-1102
1-800-552-8969

Claremont
408 Moody Building
Trement Square
Claremont, NH 03743
542-8795
1-800-562-3994

Manchester
795 Elm Street
668-2900
1-800-562-3174

Portsmouth
Simeon Smith House
Portsmouth, NH 03801
431-7411
1-800-334-3135

Concord
15 Green Street
Concord, NH 03301
224-3333
1-800-634-8989

APPENDIX L
OTHER RESOURCES

(This is a list of some of the groups which provide information, services and advocacy for people with disabilities. This is not a complete list and is not intended to be a recommendation.)

Disabilities Rights Center
(Legal assistance and advocacy specific to disabilities Issues)
Concord
Main Street
P.O. Box 19
Concord, NH 03302
1-800-834-1721 or 228-0432

Office of Public Guardian
Concord
10 White Street
Concord, NH 03301
224-8041

New Hampshire Developmental Disabilities Council
(Advocacy for people with developmental disabilities)
Concord
The Concord Center
10 Ferry Street, Suite 315
Concord, NH 03301-5022
TTY/TTD 1-800-992-3312 or 271-3236

Association for Retarded Citizens of New Hampshire
(Public information, advocacy and special projects for people with mental retardation)
Concord
The Concord Center
10 Ferry Street, Unit 4
Concord, NH 03301
1-800-828-9997 or 228-9029

The Institute on Disability
(Technical Assistance, Research, Demonstration and Advocacy regarding services to children and adults with disabilities)
Central Office
Morrill Hall - 3rd Floor
Durham, NH 03824
862-4320

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Statewide Systems Change Project and Natural Supports Project
The Office for Training and Educational Innovations
The Concord Center, Suite 316
10 Ferry Street, Unit 14
Concord, NH 03301
228-2084

Technology Partnership Project
The Concord Center, Suite #307
Ten Ferry Street, Unit 14
Concord, NH 03301
224-0630

A Home of Your Own - Home Ownership Project
Heidelburg-Harris Building
125 Technology Drive
Durham, NH 03824
862-0550

New Hampshire Partners in Education
(Statewide support to local schools to promote, maintain, partnerships)
Concord
196 Bridge Street
Manchester, NH 08104
662-5711

NH State Council for Vocational Education
Concord
The Concord Center
10 Ferry Street, Box 25
Concord, NH 03301-5022
225-4629

APPENDIX M

Adaptive Technology

(This is a partial list of the agencies which can help with information and services regarding adaptive equipment and custom modifications)

New Hampshire Adaptive Technology and Equipment Center
P. O. Box 270
Laconia, NH 03247
524-5373, Ext. 280

Technology Partnership Project
Institute on Disability
The Concord Center, Suite 307
10 Ferry Street, Unit 14
Concord, NH 03301
224-0630

APPENDIX N

Recreation and Leisure

(This is a partial list of organizations which provide activities and information about recreational activities)

New Hampshire Special Olympics
(603) 624-1250

Very Special Arts New Hampshire
P. O. Box 2338
Concord, NH 03301
228-4330

New England Handicapped Sportsman's Association
P. O. Box 2150
Boston, MA. 02106
1-617-424-1026

Association for Retarded Citizens - (see Appendix L)
Sponsors Rainbow Theater